Chapter 1
Our First Child

Lights twinkled in the great golden arches of Chicago's Auditorium Theater where Rudolf Nureyev had danced, Van Cliburn had played Tchaikovsky's first piano concerto, Count Basie had jumped around the clock, and punk groups had reduced the grandeur of the hall to a wild, echoing stadium. Tonight the faculty of Kenwood High School occupied the stage, and the auditorium seats were filled to overflowing by parents and families.

The line of students approached the platform, "Division 250, Special Education, Andrew Wyllie, Dean's Honor List." Attired in a pale blue cap and gown, his face beaming with pride, Andrew marched flat-footedly across the stage. He embraced and kissed his teacher, shook hands with the principal, and received a diploma that was proof of his graduation after four years in Kenwood High School.

As I stood to applaud, I felt immeasurably proud and wished I could encapsulate this special moment. Then tears clouded my vision as I remembered the occasion nineteen years earlier when we had waited all night in County Hospital, Bellefonte, Pennsylvania, for the birth of our first child. The date was April 21, 1959. At last the pregnancy was nearly over. I had looked forward to our baby's arrival with excitement and nervousness. As with most first babies, the labor was long and arduous, extending into the early morning hours. At 6:00 a.m., the doctor had just left to get some coffee when I felt a great urge to push. Hastily, I was wheeled into the delivery room and given some anesthetic.

Before I knew any more, I heard a voice saying, "Mrs. Wyllie, you have a baby boy."

"Can I see my baby?" I replied groggily.

"Oh, he's being cleaned up just now. You can see him in a little while," a nurse mumbled.

I vaguely recalled pictures of mothers holding their infants even before the umbilical cord was cut and wondered why I couldn't see my baby.

Drifting in and out of consciousness, I saw the bright lights in the hospital theater and was aware of a general mood of bustle and efficiency. Soon I was being taken out to the recovery room. As I lay on the hard, uncomfortable hospital cart, I became more fully conscious, and a feeling of euphoria came over me. I experienced an overwhelming sense of joy that our baby, the son I had hoped for, had been born.

At that moment the doctor and my husband, Pete, came and stood on either side of the gurney. As Pete took my hand, I smiled and started to say, "Isn't it wonderful? It's a boy." Pete's eyes looked strange, and his voice seemed to quaver as he spoke, "Yes, but we have some bad news."

I thought, *Oh my God, what's happened? Was something wrong with our baby*? In the distance I heard Pete saying, "Our baby isn't quite right; he's mongoloid. He is going to be physically and mentally handicapped."

"Mongoloid, handicapped! Why? What happened? What does it mean?"

I don't remember any more words, explanations, or expressions of sorrow. I just remember the awful feeling, a kind of sickness, the blankness and darkness of a candle flickering and sputtering and finally going out for lack of oxygen.

Several months later, Pete told me how the doctor had broken the news and put the burden on him as to how and what to tell me. Pete said, "I was waiting anxiously in the lounge, when Dr. Collins walked in and said, 'Congratulations, it's a boy.' I felt a glow of warmth and a distinct feeling of triumph for a new child before I heard the doctor saying, 'but come outside for a minute; I have something to tell you.'"

Pete remembered feeling worried. He told me, "Flashes of memories about the things that can go awry in Nature's great procreation experiments darted through my head." His first concern had been for me: "Is Romy all right?"

Dr. Collins had said reassuringly, "Oh yes, she's in good shape, but I'm afraid the boy is not quite right."

Pete recalled, "I felt sure our baby must be right. He had been born, and we were now parents. I felt bewildered as the doctor tried to explain, 'Your child is mongoloid. There are signs—the fingers, feet, eyes, shape of head.'"

Pete had asked the doctor what he meant by "mongoloid" and if there was anything that could be done. He told me, "I had faint memories of the term Mongolian monster being used to describe deformed kids and village idiots."

The doctor had painted a grim picture. "The child is mentally retarded. He will never grow up to be a normal adult. Sometimes the best policy is to inform the mother, before she even sees her baby, that the child has died and then place him immediately in an institution."

Pete told me, "I was confused. I thought about how we had made this baby together and you had grown him."

The doctor's suggestion to put him away forever was so shocking. How could we discard him? Who would want that? I imagined a tabloid report: *The doctor and the father conspire to destroy the evidence of the mother's labor. Nine months of production wasted. Mother told, "We are sorry, but your child was not perfect. We sent him away so that you can try again, unbothered by the knowledge and sight of your first, unfortunate error."*

Pete continued, "I felt my mind going numb. I used to wonder about the meaning of that phrase. How can the mind go numb? Now I know. It's like a creeping paralysis, questions half formed and never spoken. The electric impulses within the brain and from brain to tongue are derailed or shunted into cul-de-sacs. I heard the doctor's statements but didn't comprehend them."

Pete explained how the numbness slowly dissipated. "One thing became clear: I couldn't make this decision alone. I felt strongly that this baby was our joint responsibility. I decided you should be told right away because I knew you'd want to be involved."

We could only afford a semi-private room, but in the circumstances the hospital decided not to give me a roommate. As the nurses were helping me into bed, the doctor joined us and tried to explain. He knew little enough about "mongolism," now termed Down syndrome. Indeed, at that time there was little to know. He had witnessed only one other Down syndrome birth, and in that case the baby was taken away and the mother never saw her child. In spite of his limited experience, Dr. Collins was sure of his diagnosis because there were certain characteristics that distinguished a Down syndrome child from a normal child. He told us what he knew: the child's fingers were short and stubby, the toes unusual, the feet squat, abdominal muscles had an indication of an

incipient congenital hernia, the head was small, the forehead narrow and flat, the nose almost nonexistent above a slack jaw, and the mouth was occupied by a tongue that was too large for it, with a "fissured," cracked surface. The facial features, up-slanting eyes, and a fold of skin at the inside corners were the obvious oriental touches that inspired the horrible phrase *Mongolian Monster* or *Mongolian Idiot*—one title fearsome, the other pathetic.

The doctor explained that in addition to being mentally handicapped, the boy would also suffer physical handicaps. He would have poor muscle tone, and all his joints would be slack or double-jointed. He told us Down syndrome children were usually susceptible to respiratory ailments and often died young from complications. (Was he trying to give us hope that our son might be overtaken by pneumonia at a young age?) He went on to recount some brighter aspects. The children were happy, cheerful, and easy to handle. They were children who never grew up, like Peter Pan and his friends in Never Never Land.

Dr. Collins suggested we get a second opinion, just to be certain. The local pediatrician eventually examined our baby on his rounds, confirmed the obvious, told us nothing directly, and later sent us a bill for $25 (a lot of money for a student in 1959).

I found it hard to concentrate on the doctor's explanation. My head felt heavy, my eyes stung, and my thoughts were fuzzy. I tried to rest but was too upset to be able to relax. When Pete returned in the evening, we tried to discuss our options sensibly, but we felt overloaded by emotion and confused by the lack of information. Following our natural nurturing instincts, we agreed unequivocally that we couldn't "put our child away" as the doctor suggested. We decided to keep him, at least for a few months, so we could give him a good start on life. We would make a final decision later when we were better informed and had a chance to see for ourselves how he might develop.

After Pete left and the nurse had turned out my light, I finally let go and cried myself to sleep, thinking that I would wake up to find the bad news was a horrible mistake, a nightmare that was not real. But as the morning light turned the window blinds into luminescent panels, the wailing of hungry newborns, like bleating lambs, reminded me all too clearly that my baby was different.

I waited anxiously for the nurse to bring him from the nursery. I had seen him only briefly, and then he was bundled up in blankets. Now with my dreams of a beautiful and perfect child cruelly shattered, I had mixed emotions when I looked at the tiny object in its hospital bassinet. It was ugly. In addition to the features that the doctor had described, the cheeks were plump with funny, full jowls covered in a kind of furry fuzz. But this strange thing was a baby—our baby. He breathed and squirmed. He made little gurgling noises and opened his mouth, searching for food. He was soft and warm to touch, and when I held him, carefully supporting his wobbly head, my nostrils were filled with the sweet perfume of baby lotion and talcum powder. How could we discard such a little creature? He was a human being. As a mother I felt an inescapable urge to protect and comfort him.

The next few days in the hospital were full of sadness and anxiety. After discarding our carefully selected list, we struggled to choose a name. We had planned to call our first son after my father, who had died suddenly on the eve of this fateful year. I had last seen him in Scotland three years earlier, just before we left on our sea voyage to America. As I hugged him and said good-bye, I had a disturbing premonition that I would

never see him again. Now it did not seem right to perpetuate his name in our less-than-perfect son. In telepathic fashion, recalling the university where we met and the patron saint of our Scottish forebears, we chose the name Andrew.

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Both Pete's grandfather and my father were Scottish. After serving in the medical corps in World War I (1914–18), my father had set up his practice as a general surgeon in Hull, England. He was highly regarded in the community and was known for pioneering orthopedic work with crippled children. He believed that children could be fitted with prostheses at a young age and taught to use them. The prostheses would be adjusted and enlarged as they grew. Sometimes he took me with him on his visits to the Hospital for Crippled Children.

Like most children, I reacted with curiosity and scorn when I saw odd-looking people. I probably stared or snickered and then quickly looked away. No doubt my father felt that exposure to children who were physically deformed would teach me something about the reality of life outside the sheltered environment of my home. I remember that the children were always excited to see Doctor Blair. Invariably they were cheerful and eager to show off their activities using their new arms and legs. However, these children were not only crippled; they were poor. They came from the slums, the other side of the tracks. They were different, and their disabilities were something that would never touch me.

I admired my father's work, but I was never interested in pursuing any of the professions related to medicine. After spending eleven years at English boarding schools, I studied English and history at the University of St. Andrews in Scotland. I met Pete during my last year. We were married in 1956 on a cool gray June day in a small village church in Yorkshire, England. It was a formal affair, with the men attired in black tailcoats and gray top hats and the women showing off their milliners' best creations. I wore a long-sleeved cream brocade dress with beaded collar and cuffs. Two college friends were my bridesmaids, and a young cousin in kilt and sporran was my page. The reception for 150 guests was held in a marquee in the garden of my parents' home. The climax of the day came as we cut the wedding cake with my father's World War I ceremonial sword.

Before our wedding, my mother was a little shocked to learn that as members of the modern generation, we were going to plan our family. However, as Robert Burns wrote:

> the best laid schemes o' mice an' men
> Gang aft a-gley (Go oft astray)
> An lea'e us nought but grief an' pain,
> For promised joy.

Although Pete was still enrolled for his doctorate at the University of St. Andrews, Scotland, he had taken a full-time position as a research assistant in geology at the Pennsylvania State University in America. A Fulbright travel grant allowed us to stay in the United States for three years but stipulated that we must then return to England. We planned to wait two years to start our family so Pete could finish his PhD thesis and

start his professional career. We decided that our first baby should be born a few months before the summer of 1959, our final year. In July and August of the previous year, we went on a six-week camping trip to explore the western states. It was an exciting journey for a young English couple, driving across the vast plains and endless prairie lands of the North American continent, and seeing the dramatic scenery of the Rockies and the spectacular beauty of the national parks. By the end of our trip, I knew I was pregnant. We decided that conception must have occurred one night in the Badlands of North Dakota, a location that seemed especially prophetic as we looked back.

Except for morning nausea and feelings of tiredness in the first trimester, my pregnancy was easy. We were both young and healthy and had no reason to anticipate any problems. In the 1950s, there was no way to determine the health of an unborn child because procedures for prenatal testing of an embryo had not yet been developed. The most our doctor recommended was a regular checkup and a sensible diet.

When I was eight months pregnant, we saw a film about a family with a handicapped son who was cared for by a black nanny. That night I dreamed we would have a developmentally disabled child, and somehow the presentiment never quite left me. But it was still far removed from reality; it was just a dream. One day I read a pamphlet about birth defects, but again I thought, *Oh, it won't happen to us.*

Now, to my horror, it had touched us. I had given birth to a mentally disabled child. I had failed in my role as a mother and bearer of this infant. I felt responsible for this tragedy and was wracked with shame and guilt. What had I done wrong? I had given up cigarettes and coffee. I had drunk milk every day and eaten detestable liver every week. Why had God punished us?

Pete was wonderfully supportive. Andy was his baby too, and we shared our emotions and talked about our feelings. Although we mourned for the perfect baby we had expected, Pete encouraged me not to think of this as God's punishment but as his gift. We had been chosen to bear this special child and give him the best life possible. Later we came to realize that, through our child, we could help other people. However, it was too early to look into the future. First we had to learn to accept our baby and make the best of him.

After six days in the hospital, we dressed Andy in his new garments, wrapped him in a beautiful shawl crocheted by a friend of my mother, and took him home to our small apartment in State College, Pennsylvania.

Book Title: Loving Andrew: A Fifty-Two-Year Story of Down Syndrome

Author: Romy Wyllie

Availability: https://www.amazon.com/Loving-Andrew-Fifty-Two-Year-Story-Syndrome/dp/1478298340/ref=asap_bc?ie=UTF8

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