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## Down's, but not out

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**By** Charles Church

During the holidays, like many other people, my thoughts turned to my childhood family. Some of the characters I recall quite vividly, and one stands out in my mind particularly. Her story, which began in adversity, winds up happily.

Aunt Barbara was her official title, but I never heard her called that. Rather, when I was a boy, Bobby was that very different younger sister of my father who still lived with my grandparents, looked unlike anyone I knew. In a family of tall people, Bobby was short, flat-faced and bottom heavy.

What follows, for the most part, cannot be documented, so my memory will have to suffice. She was born around 1917, just as World War I was ending, the youngest of three children. Grandmother Church was of advanced age for childbearing. When Bobby was delivered, the doctors immediately worried aloud to my grandfather, the paradigmatic self-contained New England Yankee, that she had a "Downsy" look, as they described it then. That hunch was surely confirmed early on, for Bobby was a Down's syndrome child.

At some point, well-meaning doctors had the "talk" with my grandfather. They spoke of how handicapped Bobby would be, if she lived beyond infancy at all. Severe mental retardation, stunted growth, short life expectancy and more. How much she could learn wasn't known. Public schools were out of the question then, and private schooling or tutoring would be expensive. And, the doctors said, the toil, compassion, patience, energy and determination required to raise and keep her would be incalculable. No doubt they felt it was an easy decision: Bobby had to be put into an institution.

My grandfather, you should know, was a no-nonsense man. Surely he listened intently as they made their case airtight. Then, the story goes, he simply said. "No, she's one of us, and we will keep her." Any protestations from the doctors, I can tell you to a certainty, would have been wasted breath. Bobby would stay.

It was for the best that she did. One reason was Bobby's sunny disposition. She laughed hard, with great joy. Those moments brightened our days. Bobby was the gentlest of souls.

During my boyhood and adolescent years, Bobby was a source of great confusion for me. But by

the time I was asking my callow and worried questions, many real ones had been figured out. She not only stayed with my grandparents, she was a productive member of their family. No one made the terrible mistake of expecting too little of her. She made beds, did laundry, set the table: tasks that may sound menial, but Bobby was happy to do them. Proud. She could write a little, and when relaxing, she would knit.

My father, whom she adored, taught her to swim the breaststroke. During summer vacations at Lake Winnepesaukee, my father and I would wake at 5 a.m. to go bass fishing, and Bobby happily would come along. She would squeal with glee when she hooked a sunny, and her face would glow when she boated it. Then my father would intone: "Snappy work."

In every way, save one, Bobby was a full-fledged member of the family. Bobby wanted to get married, and she talked about it a lot. I'm sure it was my grandfather who spoke with her about marriage. I have every confidence that he delivered that crushing disappointment to Bobby with both kindness and firmness, but I recall hearing that Bobby used to cry after that.

One problem the family and Bobby had to face as the years went on: What would happen when my grandparents got old and died? But my grandfather also had taken care of that. He funded a trust that would pay for Bobby's expenses. Crucially, standing in the wings was my beloved Aunt Frances, Bobby's older sister, who lived on a chicken farm in Toms River, N.J. Bobby would spend the rest of her years with Franny and her hypertensive, legally blind and wonderfully funny husband, Uncle Dick.

Franny taught me what feminism was about before I ever heard of the term. Nearly 6 feet tall, she was built to last. She was endlessly inquisitive, and loved to travel and do new things. She had many friends, who arrived by arrangement or, more often, just dropped in. The front door was kept unlocked, and in they would come, perhaps giving a knock first, but many times without.

When people entered, they invariably would seek out Bobby. Not just to "say hello," but rather to sit down with her and talk. How was she feeling? What was going on in her life? No one told them to do that. They simply wanted to spend substantial and genuine time with Bobby.

Down's people had notoriously short life spans when Bobby was born. So it was wondrous that she lived to 68 years. I have always thought that one important explanation for her remarkable longevity was that Bobby had been loved every step of her way. What I will always wonder, though, is who got the greater gift? Bobby, or those who knew and loved her, who learned from her to have a little more understanding and a bit more patience?

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