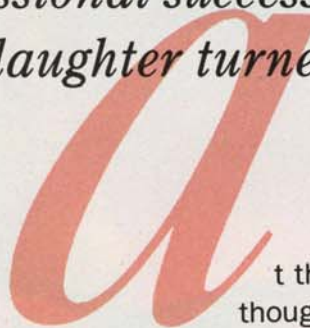


THE BIRTH OF A DISABLED CHILD

For Cathy and Don Evanochko, life was sweet. They had three beautiful daughters, a lovely home and professional success. Then, three years ago, the birth of their fourth daughter turned their lives upside down

By Suzanne Zwarun



At the back of virtually every pregnant woman's mind is the thought: "What if my child is born disabled?" With the birth of a healthy normal child, she feels flooded with relief. There will be no terrible burden to be shouldered, no heart-wrenching sorrow because she has brought a sick or damaged child into the world.

Such thoughts occurred to Cathy Evanochko, now 30, during each of her four pregnancies. As a teen-age volunteer in a Calgary hospital, she had been horrified to see pitiful babies struggling to gain a grasp on life. "They broke my heart. I didn't know how parents could live with such a thing." With the certainty of the young, she knew she would never be able to cope with the tragedy of a flawed baby. And it seemed she would never have to: three beautiful blond babies—Amanda, now 9, Melissa, 6, and Katrina, 4—were born to Cathy and her husband, Don, now 32, who designs and sells industrial hydraulics systems.

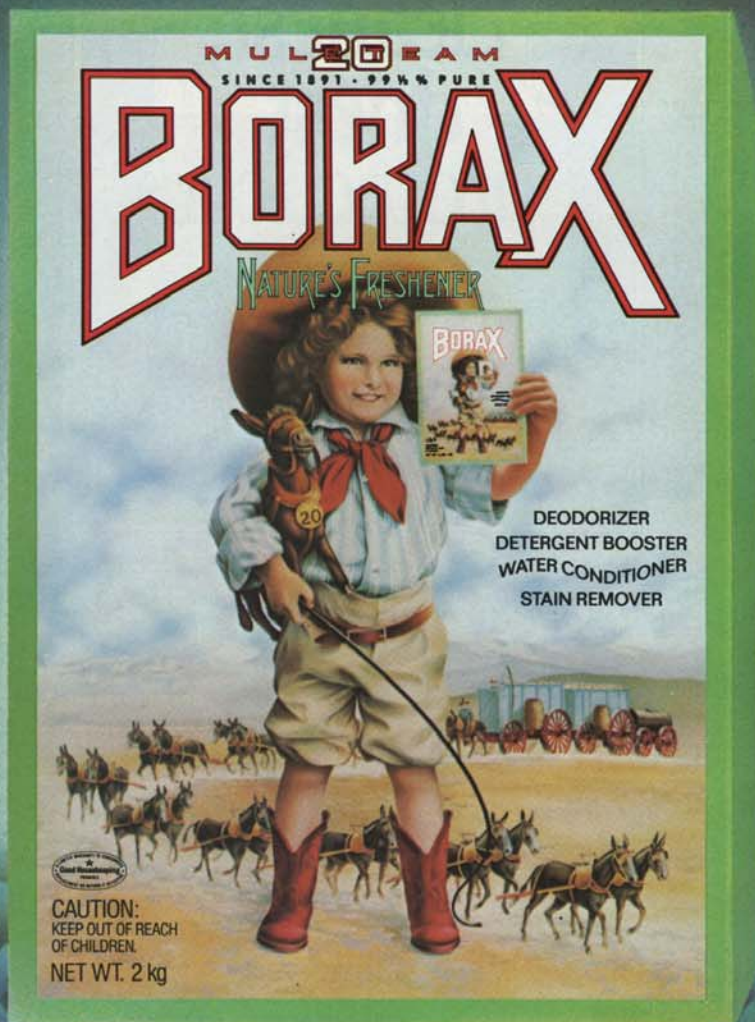


The Evanochkos (Kimberly, far right)

Their fourth baby, Kimberly, looked equally exquisite when she arrived on January 20, 1985. But their luck had run out. Angelic as the baby looked, she was the victim of a

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DISABLED CHILD

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devastating genetic disease. At first, the only indication that anything was wrong was the fact that she cried constantly. A sneeze, the click of a light switch, would set her off. "She sounded like a wounded animal," says Cathy. "It was more screaming than crying." Colic, said the doctors, and Cathy, at first, refused to let herself worry.

Six months later, Don, who had wound up his business the previous March, a victim of Alberta's recession, and moved the family to Edmonton, grew disturbed by little oddities—Kimberly's occasional blank stare, her reluctance to move around or to smile. Again, the doctors assured the couple that Kimberly was developing normally.

Then, one morning in October, Kimberly had a spasm as Cathy woke her for nursing. For a moment, her head lolled back, and she grimaced. A couple of days later, again as she awoke, Kimberly had another longer spasm. The terrified Cathy called out to Don, who took one look at Kimberly's rolling eyes and contorted face and raced her to the hospital. But after a thorough examination, every test proved normal.

In October, Kimberly had her first grand-mal attack. Cathy and Don, who had been transferred to Calgary, were packing for the move. When Cathy wakened Kimberly, she went into full seizure, turning blue, vibrating, foaming at the mouth. Cathy still hears, in her head, the scream that brought Don running. They rushed to the car with her, Cathy barefoot in the snow. After an even more exhaustive examination at the same hospital, the doctors pronounced Kimberly epileptic and prescribed phenobarbital. Their words struck fear in Cathy's heart, but the doctors were blasé—certain types of epilepsy are common in children of Kimberly's age, she was told, and nearly all outgrow it.

"I tried to relax," says Cathy, but as Kimberly approached her first birthday, she began to have choking spells—new little seizures that happened half a dozen times a day—and despite medication, the grand-mal seizures resumed. In January 1986, Kimberly was referred to a Calgary pediatrician, who recommended immediate hospitalization.

The Evanochkos spent hours at the hospital, detailing their healthy family's medical history, arguing with the doctors that there couldn't possibly be anything genetically wrong with Kimberly. Finally, a doctor trained an ultraviolet light on the baby, and Cathy gasped. "She was covered with white spots, glowing dull mauve in the light. He counted 20, gave up and said, 'I'm pretty certain that she has tuberous sclerosis.'"

Don and Cathy had never heard of the genetic disease and went home in a state ▶

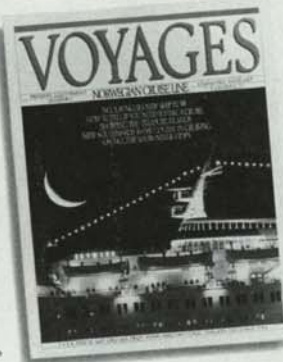
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of shock, clutching the pamphlet the doctors had given them. Its opening paragraph was devastating. TS is characterized by seizures, mental retardation, benign tumors that can occupy any organ, including the brain and heart, and lesions that can produce gross skin deformities. Once thought rare, tuberous sclerosis is now believed to occur as often as one in 10,000 births, and while most cases are mild and often misdiagnosed, TS at its most virulent is a killer: 5 percent of children die before they're 5.

TS is just one of the major congenital defects affecting three of every 100 babies born annually, a figure that has not changed substantially since early studies dating from the 1890s in Denmark. Birth defects are the sixth largest cause of death in Canada—1,600 of the 25,000 babies born each year with some defect will die before their first birthday. Many birth defects happen by accident, the result of natural genetic variation, and there are no easy or obvious ways for medicine or maternal caution to prevent them.

Some parents abandon hope when the unthinkable happens. But if the Evanochkos have, at times, wept and despaired, fought with each other and with their doctors, walked through the days like automatons, they've never ceased battling for their daughter's life. "This is my child," says Cathy fiercely. "She's a special kid."

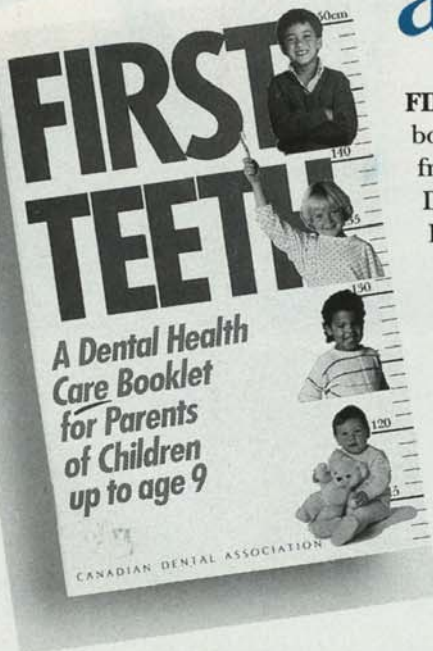
Born in Moose Jaw, Sask., Don met Cathy when she was in high school in Calgary, where he moved in 1971 looking for work. After graduating from high school in 1975, Cathy enrolled in the education faculty at the University of Alberta in Edmonton, while Don began working his way up through the ranks of the hydraulics business in jobs that took him around the province. Cathy dropped out of university after two years to go to work managing a gas station's snack bar. She had intended to finish her teacher training, but by late 1977, she and Don had settled in Calgary, and she was expecting their first baby.

Married in 1980, the couple almost took for granted their first three "wonderfully healthy" children, engrossed as they were in making their mark in the world. Not yet 30, with Cathy working between babies for an advertising agency and Don securing ever better jobs in the hydraulics industry, they quickly amassed all the trappings of the good life—big house, nice furniture. Enterprising Don launched his own initially successful, family-financed hydraulics company in Medicine Hat, Alta., in 1982.

The news of another child on the way caused Cathy an occasional quailm, but Don's excitement and her trouble-free pregnancy reassured her. The delivering doctor's congratulations echoed their own thoughts: "When you do something right, you keep right on doing it."

A year later, they were faced with the shocking diagnosis of tuberous sclerosis.

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As the hospital set out to find medication to control Kimberly's seizures—then coming in a series of 20 to 30, five to seven times a day—they took up 18-hour vigils over her. Cathy spent all day at the hospital while neighbors looked after the other children. Don would pick up the children after work, feed them dinner and drive with them to the hospital, where he would stand watch over Kimberly until midnight, while Cathy drove home and put the other children to bed. After three weeks in hospital, Kimberly went three days without a seizure and she was allowed to go home, where she seemed well at first. "She's so stubborn, such a fighter," says Cathy, who thinks that this is her daughter's most endearing characteristic. "Once she figured out walking, she worked at it until she could do it." The day she took her first step, Cathy sat down on the floor and cried.

The seizures resumed within a week, however, and although they were controlled again with each new medication, they eventually worsened. Kimberly, who had begun to talk before Christmas 1985, had not spoken since her first hospitalization in early 1986, and then she lost the ability to walk—another day when Cathy sat down and cried, this time in sorrow. By May 1986, Kimberly couldn't even sit up, and her parents were frantic. Kimberly was now having a series of 70 seizures eight times a day.

"You could see the light in her eyes go out," says Don. "It's hard to explain to a doctor, but she was dying a little every day." The Evanochkos turned to North America's foremost expert on tuberous sclerosis—Dr. Manuel R. Gomez at the Mayo Clinic in Rochester, Minn. Kimberly, then 1½, was completely evaluated there the last week of June 1986. The Evanochkos had known she had tumors on the retinas of her eyes, but the Mayo traced her seizures to calcification of the brain where tumor cells had died. The Mayo also found previously undiscovered heart tumors, which can quickly kill TS victims, but Kimberly's didn't interfere with her heart's function. "We got lucky," says Don, without a trace of irony.

The Evanochkos now faced their most agonizing decision. The Mayo recommended adrenocorticotrophic hormone (ACTH), a drug that can control TS seizures, temporarily or permanently, although no one knows why. But side effects—temporary cessation of growth, hyperactivity, hypertension, stomach sickness—are daunting, and the weakening of the immune system, while under treatment, can prove fatal. The Evanochkos wrestled with the decision for four months while Kimberly's seizures became almost continual. As the tortured Cathy demanded of her own mother: "If we say to do this and she dies, how could I ever live with it?" Her mother's reply: "How could you live knowing she had a chance▶



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and you didn't give it to her?" On November 13, 1986, when Kimberly was almost 2 years old, the Evanochkos took the chance.

The next four-and-a-half months were unadulterated hell. Kimberly was at first hyperactive—"She went three days and nights without closing her eyes once"—then ceaselessly ill, vomiting constantly and losing weight. The Evanochkos were no longer able to maintain any semblance of normal family life. "We couldn't even talk to each other because she screamed until she was sedated at night." Cathy doesn't know how they got through the ordeal: "You just put one foot ahead of the other and do it."

Neither Cathy nor Don got any real rest, even when Kimberly slept. They bought a monitor to hear her if she had a seizure so they could leap out of bed and hold her. Medicare paid all the bills, but Don's work suffered, and he has since changed employers.

On Christmas Day, which the family spent alone, Kimberly stopped screaming. Gradually, the seizures lessened, and she grew more alert. By April 1987, when the treatment ended, the seizures had stopped, and Kimberly was responding—smiling, then laughing, playing with toys. "It's a miracle," says Cathy softly.

These days, guided by an intervention worker, who teaches parents to deal with

children who have special needs, the family has taught Kimberly to hold a cup, then a spoon. She is currently struggling with eating. She must be told to raise the spoon each time. Cathy and Don find it promising, however, "that once she finally gets something, she's got it."

So too with TS. Doctors can offer no prognosis. TS tumors don't become malignant, and Kimberly can live with the ones she has. But there's a 25-percent chance she'll develop more as she grows, and kidney tumors, for instance, can cause renal failure and death. Neither can her brain damage be assessed as yet, but the Evanochkos hold out great hope for her.

After Kimberly's disease was diagnosed, Cathy started delving into her father's family medical history, unknown to her until then because her parents had divorced when she was young. Cathy now suspects a genetic link. Her late grandfather had undiagnosed seizures, and a first cousin has an epileptic son and a hyperactive daughter who shares, with Cathy and her four daughters, the phenomena of white spots. Kimberly's older sisters do not show symptoms of TS but they may actually have the disease and, if so, could pass it to their offspring.

Cathy is haunted by the thought: "I did this to them. They can never have kids, and it's my fault." But she tries to be optimistic. "Maybe, by the time they're grown

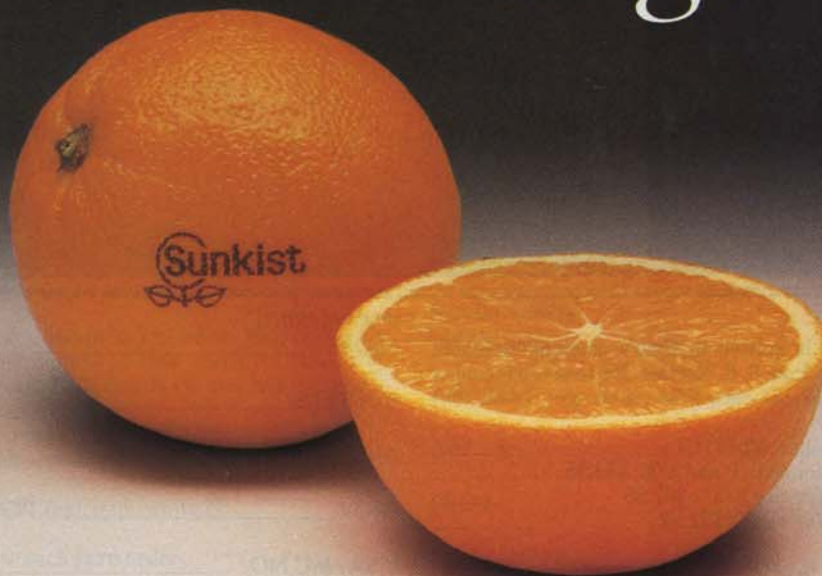
up, there will be a blood test that can prove they don't have the disease." In the meantime, the family has drawn closer together. "There have been times when Don and I wanted to throttle each other, but we love our kids too much to split up—that wouldn't help them—and we cope by trying to help other people."

The Evanochkos have become activists for the handicapped, fighting government-funding cutbacks, even educating doctors about the disease—only two of the 37 graduating doctors Don addressed last spring had heard of it. Cathy and Don are Canadian representatives for the National Tuberos Sclerosis Association, a U.S. group that promotes research and provides information for parents of TS children. They hope to establish a similar group in Canada.

"I don't know what my reasons for living were before—they don't seem important anymore," says Cathy. "Now, we have people to educate, letters to write, special teachers to see. It makes us feel we're doing something to help Kimberly."

Don too has rejected his earlier self, "when work was No. 1 in my life. We used to take normality for granted," he says. "Now, we know each of the kids is very special." Not least their youngest daughter, a child without obvious imperfections, although the disease buried in her genes remains. ●

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