

When, within a few days, she was able to comprehend and I told her what had happened, her response was, "Are you serious?"

Riding a Roller Coaster

Ever since Rebecca's desperate phone call at seven-thirty that fateful September morning I have been compelled to write it all down. One never knows, an accurate record of events might be critical. After an unsettling race to the airport for a flight to Calgary later that day, I had just missed my plane. At the airport, with three and a half hours to fill before I could get to the hospital, I began to write. Writing came automatically, a habit formed during my 26 years with the RCMP. I had always carried a small notebook to scribble anything that seemed worthwhile or out of the ordinary.

Now, three years later, I am still writing the chronology of events that turned hours into days, days into weeks, weeks into months, months into years. Encephalitis. The very word conjures up mystery and fear. Encephalitis – if not diagnosed and treated in time – can be fatal. At the time this roller-coaster ride started for our family we didn't really know anything about it. We didn't even know Becky had it. In fact, we had no idea what was wrong with her, only that she was now comatose, all alone, in a hospital. And it happened so fast.

This story is an account of the dreadful force of this disease and the long-lasting after-effects of its assault on our middle daughter. Encephalitis is a rare virus that attacks the central nervous system, invading the human sanctum overnight. Like a masked bandit, it is difficult to identify, almost impossible to arrest – and escapes with its victim’s most precious possessions – body, mind, and soul. Often, these possessions are never fully recovered.

Welcome to Rockyview ICU

Thursday, September 26, 1996

1:30 p.m.

Rebecca arrived in Emergency at 1:30 p.m., immediately had a violent seizure, and stopped breathing.

4:00 p.m.

The resident doctor is briefing me on Becky’s condition and diagnosis. My God, this is worse than I ever dreamed... “and she hasn’t regained consciousness,” he was saying. Oh God, what’s happened to her? The resident continued ... “She’s under heavy sedation and on life support. You can see her. But I must get clearance first. It’ll only be a minute.” A half-hour later they usher me in. I have donned a gown, had a sterile wash, and clumsily tied on a face mask. My little girl. My poor little Becky girl. Have I come in time? “It’s Dad, Becky. Dad’s here. You’re going to be okay.”

Her chest slowly rises and falls as the ventilator methodically breathes into her lifeless form. Her beautiful eyes are closed as if in sleep and the crisp starched pillow cradles her head of honey curls. Monitors pulse, tracking every vital body function. Other equipment pumps life-sustaining fluids and medications into her weakened body. She needs them to survive. “Hold her hand till I get there, won’t you?” her mom Pat had implored through her sobs over the phone.

I glance down at Becky’s limp hand. It looks so frail in my own hand. I note that she is still biting her nails, a habit, along with smoking, that she is trying to stop. I kiss the pretty fingers that are so adept at the computer, reflecting on her

creative ability to write and plan. Will her fingers ever be strong again? Will she ever be creative again? I want to hold on and squeeze health back into her – and – never let go.

My race to the hospital...

September 26, 1996

Early afternoon

For me, time took on a whole new meaning on that fateful day. I will never again describe a minute as having 60 seconds. On September 26, 1996, time gyrated from ten seconds to an hour. It flew by mercilessly when I frantically dialed travel agents, airlines, the airport, trying to catch the earliest flight to Calgary. Then the clock suddenly accelerated, with only half an hour to grab my shaving kit and put on a clean shirt, I rushed to the airport. I missed the plane. I had made it with three minutes to spare and the departure people had been asked to hold it. But it took off while I was getting my ticket. Two hours to kill before the next available flight. Three and a half until I could get to Becky. Time suddenly stood still.

I called Pat. She was staying in close contact with Becky's good friend Lynette in Calgary. Thank God for Lynette. She had rescued Becky at her house and called an ambulance. I was to meet her at Rockyview Hospital on my arrival. Now I would be two hours late. Two precious hours.

There is nothing to read on the flight so I continue to write down my thoughts. It is a good idea to record the sequence of events. I know that, at times like this, it will help refresh my memory later. You never know, depending on the nature of the problem, it could develop into days. Even a week. Might be a nervous breakdown. She has really been pushing it at work. And that miserable cough she has been unable to shake. Then there is her unhappy relationship. Little did I know.

When I arrive at the hospital, after a cab ride through Calgary just barely ahead of the rush hour traffic, Lynette is waiting for me, almost frantic, wondering what went wrong with the timing.

ICU Family Waiting Room

September 26, 1996

9:00 p.m.

Now, later in the evening, Pat and our oldest daughter Debbie arrive. I brief them cautiously in the family waiting room, which is situated outside the ICU (Intensive Care Unit) swinging doors. I have no idea that this little room, which has been the scene of so much grief and relief, will become our second home for some time.

We are told that there is room for cautious optimism. Becky's vital signs, heart, pulse, lungs, etcetera are strong. It is too early to tell. There has been a fluttering of her eyelids. But that damn racking cough. At least it is an indication of irritation, a sign that her sensory system is still active.

You hope. You hope and pray when you hold the hand of your comatose loved one and whisper to her that you love her, that you are there to help her get through this, that everything is going to be okay. You hope through some miracle, in the creativity of life, your message gets through. That she does hear and somehow understands. You believe she does receive strength and courage and hope through your hands and voice. And you come away assured that the magic flows both ways, from your body to hers and back to you. That a father's prayers and kisses and tears can be absorbed by a child. That her mother is strengthened by that knowledge. That we are all strengthened by that knowledge.

Flashback...

1975

The year is 1975. We are living in Swift Current, Saskatchewan where I am stationed with the RCMP. It's 4:30 p.m. and Becky and I are just starting out on her paper route. She has piano lessons at 6:30 p.m. I am helping her deliver *The Advertiser* so that she can finish with enough time to have supper before she leaves.

She looks up at me with her shy smile and bright beautiful eyes, a quiet unassuming girl who goes about her business in an organized methodical manner. She halfs-up the papers, then says, "I'll take one side of the street Dad, and you

take the other. You put a paper in every mail box, 'cause they're free." And away we go. The money she earns is carefully recorded and carefully spent. Never on herself, unless for additional school supplies. Her personal Birthday Book attests to the great number of cards and stamps she buys and to all the generous presents she purchases for her friends and family on special occasions.

I remember that, the year before, she had saved enough money for a new bike. But, because she is the middle child, she settled for a hand-me-down, and bought a savings bond instead. Once, she confided to her closest friend that, being a middle child, "You hardly ever get anything brand new."

When I tucked her in later that night saying, "Good night, sweet dreams," she handed me a little hand-made Thank You Dad card and peacefully went to sleep.

Intensive Care Unit ICU

I couldn't leave her there alone that first night. I had to be there if and when she woke up. In my mind, the scene was quite graphic. She would be unknowing, lost, scared. Absolutely devastated. As it turned out later, piecing it all together, I imagined it went like this...

Becky woke up one day in a strange bed in an unfamiliar room, with no knowledge or recollection of where she was or how she got there. She looked around fearfully. Her eyes settled on a calendar on the bulletin board. But something was wrong, the last she remembered was that it was July, maybe August, but not November! The grass and trees were green. "But it looks like snow outside the window. That's impossible." She examined the white walls, the white starched sheets, the side-table with its neat array of ice-water and face-cloths and flowers and books. Her mind raced frantically as she tried to recall events that might give her a clue – clue to what?

Her thoughts were whirling, "Who am I? Where am I? What happened to me? What's going on? Is this real? Am I real? Am I alive? Is that woman in white over there real, alive?" And then, the fear and panic, slow terrifying recognition, "She's a nurse! This must be a hospital. What kind of hospital? Oh God – no – a mental hospital!" Becky quickly felt for her arms, "They're okay," her legs, "okay, no

pain.” Her head felt okay. No bandages. “Oh God, nothing physical – then – it could be a mental hospital!” For a fleeting moment she wanted to feel a cast, bandages, anything to give her a clue.

Her panic was real now. She struggled to remember. Somewhere... some time ago... maybe yesterday? She had been a little depressed. A few things had gone wrong in her life. Her problems had seemed insurmountable. But not this serious. Maybe too much smoking? Or maybe too many drinks? She had promised herself that she would give it up, quit, sell the house and move to Europe. Start over. Ten years of ups and downs had become overwhelming. She remembered letting him in at three o'clock in the morning, the incessant pounding on the door, the violent argument. She had been talking of ending it all. But she had only wanted to hurt him, to make him sorry.

Suddenly, she felt a sharp pain in her hand. There's something there. A needle. “It's an IV! Why didn't I notice it. This is a hospital. How long have I been here? What about my job? My house? . . . My cat! Oh no. Luna. She may be starving or dying of thirst. Maybe she's waiting for me to come home. Sitting there in the window, looking for me.” Rebecca tried to remember if she had left a key with anyone. “Did Lynette have a key? Will she know that Luna is there alone?” She had to call Lynette right away. But when she went to swing her legs out of the bed they wouldn't move. She desperately needed to get to a phone. Questions were racing through her head. Her purse, her wallet, her credit cards? Where were they? She had to get to the bathroom – then quickly realized that she was also attached to another tube – a catheter! “Oh no.”

She was certain her family didn't know. She had to let them know. Let Mom and Dad back in Saskatchewan know that she was here, in a hospital. Call the nurse. Ask her to call them. They'll come. They always come. But she couldn't remember the phone number. She wondered again how long she had been there. Days? Months? Years maybe? “Oh God, maybe they're dead. Maybe I'm dead.” She wished she had phoned more often, written more often. Tears came to her eyes. She needed a Kleenex.

Then she realized that someone was handing her one. And there was a warm gentle hand on her forehead. She remembered what it felt like when her dad checked her fever when she was little. Someone was standing there beside her. She

couldn't make out the face. Her tears were blurring everything. But the voice was familiar, calm, "It's okay, Becky. You're all right. You're not going to choke. You can breathe okay. Mom and Dad are here. We're with you."

Her tears were being wiped away, gently. The faces became more clear, a gray-haired man and a pretty, middle-aged woman. They looked familiar. They could be her mom and dad. It had been a long time. "Did the nurse phone you? To tell you that I'm here?" She thought that they must be her parents because they had said, "Mom and Dad are here." Then the questions poured out, one after another, she gave them no chance to answer, just asked the next question. But they were telling her that they had been here, beside her, for a month. A month? Are they serious? She was beginning to get irritated, suspicious even. After all, she had been at work an hour or so ago. She knew. It was fresh in her mind. She'd been home already, cut the grass that morning.

They were telling her that Luna was okay. Of course she's okay, why shouldn't she be? Now they are telling her about her illness, a serious virus, a big word. What was that word? She was too tired to concentrate, too tired to try to remember. She had been sick but that was years ago. Wasn't it? Besides, why did they want to talk about that? She was back at work and better now.

Why do they have that calendar up. It's wrong. Then she knew. They were telling her she was only 31 years old. Crap. They couldn't be her parents. They're impostors! She knew she must be very careful. They were trying to trick her. She could feel something, "Oh God. Worms!" Worms crawling through her veins, She had to get that tube out fast. It was poisonous. Suddenly, they were pulling her hands away from the tube. "Hah! Wait until they're not looking. Yank it out fast. They're...aliens!"

Thus we embarked, with our Becky, on a trip of seemingly insurmountable pitfalls with mountains and valleys that we were woefully unprepared for. At times it seemed like our determination and resolve to get to the other side was the only thing that could pull us all through. We all knew, including Rebecca – that if we were not resourceful and forceful she could easily become just one more institutional inhabitant marking time – while an indifferent society marched apathetically on.

Just imagine what it would be like to take a year out of your life, and take a journey into the unknown. You would be setting aside your interests, your job, your career. You would have to forget all about your dreams, plans, hopes, and goals to tread cautiously through a labyrinth of uncertain endings known as the medical system. The system – despite the billions of dollars supporting it, the finest brains monitoring it, the advanced technology used in it, the latest scientific discovery advancing it – somehow seems to be falling down. Falling behind the afflictions that it is designed to overcome.

Who is Rebecca?

Who is Rebecca? She is the epitome of Canadian youth, carrying all of the laurels and baggage of a post-war baby boomer, basking in her 1990s yuppie lifestyle. Born smack-dab in the middle of the 1960s hip era. Rebecca and her three siblings, with their Mountie father and dedicated stay-at-home mom, enjoyed all the advantages of a secure, urban-rural, educated, refined, western Canadian upbringing. Music, sports, horses, combined with intelligence and beauty, had escalated her from the Miss Teen Canada Pageant to successful employment in the lucrative oil business. Black gold. Success in a highly competitive, high-pressure business in Canada's fastest growing city. Then suddenly, it all grinds to a heart wrenching stop.

Life for Rebecca started over again on September 26, 1996, in a place called Rockyview Hospital. What catapulted her into this new life began with a two-week coma and 26 days of therapy. Just to learn to walk again. A miraculous comeback as she fought to regain strength and identity. It would have forever eluded a less determined patient. After weeks of intense care where she progressed from her bed to a wheelchair to walking out into the fresh winter air; our Rebecca was finally well enough to travel – or so we thought.

The second stage of her recovery and rehabilitation therapy took place back home at the Wascana Rehabilitation Institute in Regina. There, Rebecca began to put the pieces of her life back together. There she struggled with the hopes and fears – the gains and the losses – of her long and seemingly endless quest to regain a normal life. Her journal gives us only a whisper of the unimaginable sense of loss and the hopeless confusion that encephalitis can inflict on its hapless victims. The only

thing predictable about this silent assassin is the uncertainty. There is no clear cause and no certain cure. And no one is exempt. Rebecca's story has all the elements of high drama – tragedy, redemption, love, anger, heartbreak, humour, endurance, rejection – and a message that reaches deeply into our reason for being.

I had a lot of time to think that first night in the hospital. I knew I had to be there to comfort her, reassure her, soothe away the fear and panic. I had to let her know she was still loved and wanted. She had no husband, no child of her own to care for or fall back on. The years of independence had taken their toll. But she still had a good position with a reputable oil company, a comfortable home with a mortgage, a car (and a bundle of bills), and her photo albums and souvenirs. And she still had Luna the cat, and her family. Time takes its toll on all of us, but Becky has youth on her side.

As I gazed through tears at her bedside, I found myself holding the hand of my little girl once again...

Flashback...

February 1982

It's 1982 and it's quite mild in Regina for February. The euphoria of just being crowned Miss Teen Regina is still around her. Becky glanced out of her bedroom window, down the street...

Cars are driving up. People are coming in. Mom and Dad are hosting a few close friends and neighbours before going down to the official reception at the Hotel Saskatchewan. "Got to get dressed." Two new outfits are laid out on the bed. One casual for now, then your gown for tonight. And don't forget the banner! Photographers, television cameras, interviews. Congratulations and prizes of all descriptions. And best of all, a trip to Toronto for the Teen Canada Pageant! "Wish Debbie would phone." Her big sister said all along she would make it. No doubt. "Debbie came so close a few years ago, first runner up. She should have won!" Becky caught a glance of herself in the mirror. Radiant, tall, beautiful, naturally curly hair. Mom's beautiful eyes, and, as Dad said, a beautiful mind to top it all off.

Christmas letter...

1982

Dear friends

You get it every year, like the common cold. You can't see it coming, but you know when it arrives. You can read the signs even though they're invisible. You know when other people have it, even though they don't tell you. It can strike you anywhere, and it usually lasts to at least December 25. It's called the "Christmas Spirit."

I've got it. I tried putting it off but here it is, my pen in hand, writing our annual Christmas letter. One's senses seem sweeter, people more friendly, everything neater. And the real swell thing is – we start thinking about old friends and relatives – and that's where you come in. Now, I'm not saying we didn't think of you all year. Heavens, no! It's just that now we take the time to sit down and tell you so. We want to hear from you and yours, and tell you about us and ours, and that way we keep the chain of life from becoming rusty. Now to start with, I have had a very dull and uneventful year – but wait 'till I tell you about – the rest of the family.

I'll start with the kids, because it seems that they get all the breaks, you know, just being young is something to be happy about. Pat and I have to settle for trying to be young at heart. School days, school days, good old Golden Rule days... This year we've got all four in school. Hard to believe? It's true, just look at my bank book, drained. Deb and David realized how great school and training can be. So Deb is in her second year of the Travel Consultant Program at Grant MacEwan in Edmonton, and will wind up her studies with a practicum in Hawaii for two weeks in April. David decided, for unknown reasons, not to pursue a "common laborer" career, so enrolled at Kellsey Tech in Saskatoon and is taking refrigeration and air conditioning. He is also discovering how many "extra-curricular" activities he missed in good old high school.

Rebecca. How that girl thrilled all of us and what an exciting time it was, the Miss Teen Regina pageant, the plans for Toronto in March, the fun trip we made (including Tricia), a wonderful visit with sister Joyce and husband Ernie, a dinner in the revolving restaurant atop of the CN Tower, a visit to Niagara Falls (Tricia's first), shopping and sightseeing in cosmopolitan Toronto – and then the grand finale – the Teen Canada Pageant. New friends, new experiences, and the myriad of gifts and prizes. Surely, a young lady's dream come true.

I suppose you could say it was also the highlight of Tricia's year. But she wasn't overshadowed in accomplishment by any stretch of the imagination. Everyone loves a winner. And everyone loves Tricia. Track and field, red ribbons, city volleyball champs, more red ribbons. And at the budding age of 12 – she touched a plateau that took the likes of Anne Murray and Harry Belafonte years to obtain – a performance at the Centre d'Arts! That's right, her dance class performed their recital there, before a packed house.

Did I say I had a dull and uneventful year? Well, you know what I mean. I didn't do anything spectacular. I'm retired. I just went along for the ride. (Pat's reading over my shoulder and she says, "Tell them about your promotion to registrar." But I'm not even going to mention it.) Pat, in her usual efficient and beguiling way, co-ordinated the children's activities, kept house, made meals, washed and ironed, planted a garden, made dill pickles and raspberry jelly, handled the bills, spent the money, worked at Sears between stints as mother and wife, and talked on the phone a lot. We visited my mother in Winnipeg and Pat's mother in Goodwater, and they are just fine.

It's been good sharing the Christmas Spirit with you. Hope to see you in '83. Oh, yes, we are expecting a visitor around December 25, a jolly fellow, with a beard and a pack over his shoulder. Know who? – you guessed it – David coming home from Kellsey, with his dirty laundry!

Happy New Year!

Barrie, Pat & Family