

Never give up hope

by Marion Hollinger with Delaine Elle

Learning we have a chronic illness can test our faith. When, at the same time that faith is brand new, only God can bring it all together.

PERHAPS HER MOST POIGNANT MEMORIES are those of sitting on the back step of the family farmhouse with her father, each trying to staunch yet another nosebleed that just didn't want to stop. It would be many years and many doctors before Delaine Parsons could put a name to this chronic, inherited condition with unusual symptoms.

Delaine, born in Westlock, Alberta, started having nosebleeds at eight months old. No one could tell her parents why. Her teenage years were filled with nasal cauterizations and packings. Many less than helpful solutions were offered by others, including, "You're just growing too fast," to explain the frequent nosebleeds she, her father and, before that, her grandmother suffered.

In 1971 she married a banker, Clarence Elle. Delaine was not a Christian. Shortly before she and Clarence were married she was baptized. Attending church, she found herself "struggling with a new language and trying to know a God I could not see, identify with or relate to." She adds, "When things are going well, life is good. I had little need for God, His love or forgiveness." She attended Bible studies, but would go home feeling frustrated, rather empty and hungry for more. A good friend, after losing her husband, had to work to support herself and two teenagers. "She always talked about God in her life and what God had done for her. I felt more like doubting Thomas."

Delaine continues, "I felt a sense of wanting our two children in Sunday school, to have something I had missed. But there were not enough teachers. I really felt tugged, not pushed, into teaching. The pastor's son and some other children who had been in church all their lives were in my grade 4-5 class. Every bit of my energy and time went into preparing lessons from an excellent leader's guide. With ten inquisitive kids, my task was really cut out for me. Learning children's Bible stories was a great place to learn the language and the message of God's love that I took into difficult health challenges eight years later.

"An Epiphany sermon asked the question: What are you doing with the Christmas gifts you received? Leaving them in a box on a shelf? We have the opportunity to know and

share the one true precious Christmas gift, Jesus. Pastor talked about heaven and hell from the Bible. I figured I knew enough about hell so I had better get busy and learn the way to heaven. That Easter took on a new and special meaning. He is Risen! Forgiveness is for me and for all God's children.

"In February 1988, when our son, Stuart, was fourteen and our daughter, Deloyce, was twelve, I got up from a kitchen chair and suddenly felt a stabbing, throbbing pain in my left groin and hip. At first it was intermittent, but it became worse and worse.

My stiff hip made it difficult to walk, sit, climb stairs, or bend over. It was only years later I became aware the pain was the result of internal bleeding."

As a banker, Clarence was transferred about Alberta and Delaine had the opportunity to consult many doctors and specialists. But none recognized the telangiectases (see side bar) in her nose. The doctors only said the blood vessels were close to the surface and bleeding around previous cauterizations. Now, unfortunately, with something more serious happening, the misdiagnosis continued. A bone biopsy for Paget's disease resulted in hemorrhage and blood transfusions. Delaine resorted to using crutches and later learned the specialist

had not expected her to walk again unassisted. The biopsy result was "benign hemangioma" on the bone. Now what? She could not tolerate the pain forever.

"God grant me the serenity to accept the things I cannot change, courage to change the things I can, and wisdom to know the difference." This is still Delaine's favourite prayer, reminding her how helpless she really was with doctors who were totally baffled by the persistent pain in her hip. "It was discouraging," she says, "but I never gave up hope. I felt like a two-year-old, always asking "Why?" or "How come?" I had little choice but to patiently wait for more appointments and tests... for 16 years. I begged two things from God—help to ease the pain and to attend our children's grade 12 graduations."

Delaine waited months for an MRI, and then several weeks for an angiogram. More than six years passed before

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Clarence and Delaine Elle

physicians identified the existence of an extensive Arteriovenous Malformation (AVM) in her hip and groin wrapped around the head of the femur. Understanding that an AVM can burst and hemorrhage, she inquired about the possibility of leg amputation. The surgeon said, "Definitely, no!" and explained that his job was to find a treatment and keep her walking. Eventually she was referred to the Toronto Western Hospital AVM clinic where a liquid glue was injected. Staff referred to it as "space-age Krazy glue." She was told it had been used on the Canadarm, the robotic appendage used outside the hull of the U.S. space shuttle. When told they could not promise pain relief, Delaine responded, "Well, I am not going home to sit in my rocking chair and wait for the lights to go out!" She remembers of her sudden outburst: "Even I was surprised, and joined the doctors in hearty laughter."

Since then Delaine has continued her battle with this strange illness called Hereditary Hemorrhagic Telangiectasia (HHT). At one point they discovered her heart was pumping three times the normal amount of blood because of the "direct connection" between the arteries and veins in her hip. Numerous screening procedures showed other AVMs elsewhere in her body. Today, though various problems persist, her chest and hip pains have been reduced significantly. "What an enormous relief," she says, "to at last get a break from constant pain!"

"It was comforting to know people were praying for me," Delaine says. "God spared my life on numerous occasions, to serve Him in an area I knew nothing about. It is important that screening for HHT be done and even more important that

doctors and others learn to recognize it. The thought of sharing my lifetime of HHT with very educated medical professionals leaves me overwhelmed, with swarms of butterflies and a numb brain. But, when I have been patient and leaned on God in the past, He has shown me the way many times.

"How have I made it through these many challenges? As it says in Scripture, God is my Rock and my Strength. As I wait on the Lord, reading His promises in my Bible renews my strength. When lying on my back in pain and looking up I try to focus on some Bible verses, sing to myself or sing along to Christian music. I visualize Jesus on the Cross for me, a sinner in need of forgiveness. His pain and suffering were much more than mine will ever be. Jesus waited patiently and followed His Father's plan for Him. Jesus is my role model. I cannot change my situation. I can submit to God's will, trust in Him, grow in faith and His grace. It does take patience to wait on His time and when He chooses to call me home. I am confident of His promise to those who believe and are baptized in His name. I will have eternal life, a home in heaven with my God of Love, with no more pain or suffering.

"God has given me life, to be a light, and to share Christ's love, forgiveness and compassion. I am so very grateful. I want to make a difference...to be a blessing to other HHT patients and their families. My motto: **Help** save lives, **Hope** for a cure, **To** raise awareness." ❀

What is HHT?

Hereditary Hemorrhagic Telangiectasia (HHT) is a genetic blood vessel disorder affecting males and females from all ethnic groups. Also referred to as Osler-Weber-Rendu syndrome or simply the "nosebleed disease," it was recognized by doctors in the 1890s who saw that characteristic red spots/birthmarks and nosebleeds in certain patients were abnormalities of blood vessels, *not* a blood clotting problem. More than a hundred years later, HHT is still often misdiagnosed and mistreated because doctors and specialists do not understand all its manifestations.

A person with HHT forms blood vessels that lack the capillaries between an artery and vein. Arterial blood (from the heart) under high pressure flows directly into a vein without squeezing through the very small capillaries. This direct connection tends to be a fragile site that can rupture and bleed. A telangiectasia involves small abnormal blood vessels, usually occurring on the surface of the skin and on the mucous membrane lining the nose. Arteriovenous Malformations (AVMs) involve larger abnormal blood vessels,

and tend to occur in the internal organs. These malformations may be "hidden" or "silent" killers.

Spontaneous, recurring nosebleeds are the No. 1 symptom for 95 percent of HHT patients. Nosebleeds are *not* normal.

About 30 percent of patients can have one or more lung AVMs. These can be disabling or life-threatening if untreated, causing strokes, heart attacks, brain abscesses, or hemorrhages (particularly during pregnancy).

About 25 percent develop gastrointestinal bleeding causing anemia, fatigue, and lightheaded feelings, because the patient may be unaware of blood loss.

Brain AVMs, found in about 15 percent of patients, can in most cases be successfully treated.

Significant progress has been made in the past 30 years in screening, treatments and research.

For more information and board-approved HHT centres (three in Canada), visit the HHT website at www.hht.org.