

John's Story

John Routely was diagnosed with acute lymphoblastic leukemia (ALL) in 1999

OUR daughter was born just nine months prior to my diagnosis. She is our first and only daughter. I was going to Capilano College in North Vancouver taking the Registered Care Aid Program. I only had my practicum left. I was very active hiking and exploring around North Vancouver. I just became a Christian and was very involved with my new church family. I was thoroughly blessed: enjoying being a new father and feeling on top of the world. My wife and I were excited about starting a family and were planning our future with no idea that I would shortly be diagnosed with such a serious, life-threatening illness.

When I was 31, I was diagnosed in December 1999 with acute lymphoblastic leukemia (ALL), Philadelphia chromosome positive. I felt disbelief at first, then scared; everything was happening so fast. I went to Emergency with jaundice one evening and was told my blood work was “wonky”. The WBC was significantly elevated, and the next day I had to have a bone marrow biopsy that confirmed acute lymphoblastic leukemia. Then the following day chemotherapy was started. My parents rushed down from Smithers. I cannot even begin to describe the shock our family was in after learning I had such an aggressive leukemia. Family and friends were contacted and began supporting and praying for us.

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I went through one round of chemotherapy. Then I looked for alternative therapies. I relapsed in July 2000 and had an unrelated bone marrow transplant on August 17th, 2000. It was a 6/6 match from a German donor.

Over the next couple of years, I had several hospital admissions totaling over one year as a patient for pneumonia and graft-versus-host disease of the liver and gut. I had one abdominal surgery. Many times I had a poor survival prognosis but was blessed with making it through these difficult times.

I stayed in remission for nearly 2 years after the bone marrow transplant, and relapsed again in 2002. I then went on Gleevec 600 mg orally. I had a very hard time taking it at first (had to take it with a strong anti-nausea medication), but eventually it became easier. Now I take Gleevec 400 mg everyday and have remained in remission ever since. I have had periodic admissions to the hospital for pericarditis, septic shock, and pneumonias. I have chronic hemochromatosis (as a result of genetics and transfusions). I will be doing

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small monthly phlebotomies. I also have kidney and liver damage which is constantly monitored and has been stable for the last few years. I have gone through periods of depression after being chronically unwell for such a long period of time, but my family and medical team is always there to help me. I visit my hematologist every six months now and recently he has been able to do a hematology clinic right here in Prince George to service the northern patients. I have had the same hematologist, Dr. Nevill, for most of my illness and I certainly want to uplift and honour him for all his professional knowledge that has saved my life!! Thank you, Dr. Nevill. I am also thoroughly thankful to my family physician in Prince George who is always there for me and provides such excellent medical care. Thank you Dr. Kelly and Anita, his assistant. All my doctors and medical staff have been excellent both in Vancouver and Prince George, and there has been a lot of them!

Has cancer changed my life? Yes, it has significantly. First, so many of my life goals were changed. My new goal became surviving for my wife, daughter and family. It also became an important goal to rebuild my physical body and to accept the changes in my life. I had to accept my diagnosis and fight the battle with all my physical strength and depend entirely on God.

There are so many people that I am thankful to for all the ways they have supported me and my family. I thank my family, my Mom and Dad, my wife’s family, relatives, friends and my church who have all been there in such a huge way to help. They offered to babysit our daughter, visited me after traveling hundreds of miles, sent cards, gave gifts, brought food, said prayers, recommended every product under the sun to cure me (with good intentions, I admit) and plainly just encouraged us all the time! My wife met many supportive families going through similar situations in the hospital hallways and kitchen. She valued all the support they gave her,

especially the support of one special woman named Yvonne Shuman. And what would I have done without all the hospital staff including the physicians, nurses, dieticians, OTs, porters and housekeepers that were so kind, encouraging, and knowledgeable in medicine and patient care. They all went well over and beyond helping, not only me, but also my wife and daughter. I had two admissions over Christmas and they made it so special for us, despite me being so unwell. Everyone was always respectful of our family’s choices, even when they may have been different than their own values and preferences. Our daughter basically grew up in the hospital and outpatient clinic from age 10 months to 3 years old. Everyone was always patient with us having a young child and allowed the occasional popsicle, in order to prevent the odd tantrum. One particular birthday, when I was nearly considered palliative care, a certain dietician named Yvonne Grohmuller blessed me with a memorable birthday when I weighed only 96 pounds. (My weight today is over 180 pounds.)

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My lifestyle changed drastically for many years. I was so sick and had no strength for approximately two to three years. I slowly gained some of my strength back and am now able to go for walks, bike rides and play with my daughter. There are a few restrictions that I have. For example, I avoid hazardous activities for falls such as rollerblading because of my low bone density, but I am slowly regaining strength every year. I have cross-country skied, camped and enjoyed short trips with my family recently.

I have not been able to return to work, but some day in the future hope to go into another career choice. Spiritually, this has been a time to learn to trust in our Creator, God, and accept that He is there when we go through sufferings and trials in life. We are now living in Prince George. At the time of my illness we were residents of Vancouver, but moved up north to be around immediate family about six years ago. We are able to enjoy nature and the beauty of this forest region, an area rich in the red pine beetle forests.

My relationship with my daughter and wife has become so close. I am so thankful how my wife has supported me and we have become closer through this experience. We really depend on each other and enjoy our time together as a family. We do not take each other for granted. I have had the chance to really appreciate my life and spend more time with my family. It has been good for all of us to learn more about ourselves and our need for Jesus. I am very aware of

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diet, nutrition and health now more than prior to my diagnosis. We try to avoid a lot of preservatives in food. I avoid smoked meats. I have become mostly a vegetarian and we have a small garden. My wife cooks in a very natural way for us. I do not drink alcohol or smoke. I drink 1 to 2 litres of water a day. I find meaningful time every day with God for strength and coping with stress. I have also let go of anger and practice forgiveness.

The hardest thing about having cancer was thinking why did this happen to me? One seems to blame himself at first, and ask God what did I do wrong? This is where the reality becomes clear that we are living in an imperfect world where children die at young ages and get sick, children starve from lack of food and disease and suffering seems to see no boundaries. To be completely honest, there has been some depression occasionally and searching for my new identity and purpose has got me down in the past and even currently if I am not keeping my life in balance physically, emotionally and spiritually. What has been

hard, at times, is when it appears people are defined by what “they do for a living” and if you do not work, one needs to define their identity themselves and accept it. At these moments of despair, my greatest strength to see me through is my faith and those closest in my life. I

have learned that God is with us in our suffering and trials and gives us the strength to live one day at a time looking to Him as our source of strength! I do not think about reoccurrence because I live day by day, spending my time in meaningful pursuits, enjoying every moment with my wife and daughter. I enjoy reading and being on the internet as well.

Something positive can come out of something negative. I now am blessed with a blood brother, my bone marrow transplant donor who lives in Germany. I have had the opportunity for the last seven years to be in contact with him. Since I have no siblings, the only chance I had medically for survival was an unrelated bone marrow transplant. I was blessed with a perfect bone marrow match to this gentleman. Over the years, we have gotten to know each other quite well. There is a language barrier, but that does not stop this awesome relationship. We send letters, pictures, emails, gifts at Christmas, postcards and even spoke twice with a translator across the ocean. We have both extended invitations to open our homes for a visit one day and it will be a dream come true if we ever could!

Surviving means the possibility to see my daughter, Cassidy, graduate and maybe even get married. I am not going to limit the possibilities. This experience, although initially one might think as very frightening, is not as bad as people think. I can see the blessings in the smaller things of life, the things around me such as nature, family and daily living. It has taught me patience, more understanding towards others who are experiencing troubles whether health or emotional difficulties and I can say that God is there for everyone. He is a prayer away and cares about all His children!

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