
Through the Eyes of a Mother

Leslie Gibbenhuck

My name is Leslie. I am 43 years old and the mother of the three greatest children in the world – Tyler (16), Ashley (13) and Jarad (11). I am married to an RCMP constable and we live in the Sunny Okanagan of British Columbia. I would be kidding if I told you our life is rosy, but we do try to make the most of it!

Our life as a family was what I frequently look back on as “normal”. Husband and wife save for a family. Wife gets pregnant, delivers a healthy baby boy. Family not complete, so they have a baby girl 18 months later. Husband works full time. Mom cares for children. A house, two vehicles, nice furniture, a savings account, RRSPs, annual vacations, all the toys and trinkets! Parents deal with common colds, ear infections and vaccination complications but, in general, health, finances and life are all pretty good!

In July 1988, our third child was born. Jarad was sick from the moment of birth but no one could find a reason for his ill health. It became apparent, two months later, that something was desperately wrong. Jarad required immediate open heart surgery. What we didn't know was that Jarad got infected with hepatitis C from one of the 23 units of blood and blood products he received during open heart surgery. He was just eight weeks of age.

On June 1st, 1995, we received the good news/bad news telephone call. Jarad does not have HIV, he has hepatitis C. Our GP informed us that he did not know much about hepatitis C, except that it used to be

called non-A, non-B hepatitis. It was actually a relief to finally get a diagnosis but I quickly learned that life with a relatively new disease was anything but smooth.

Myriad emotions have touched our lives since – confusion, guilt, frustration and anger, just to name a few. But more importantly there have been questions. Why did it take doctors almost 7 years and over 400 medical appointments, treatments, and procedures to diagnose Jarad's hepatitis C infection? Why had we not been told, when BC Children's Hospital had tested Jarad the year before and knew he was positive? Why were we being treated, by previously supportive hospital staff, with fear and reservation? Why did this happen? What will his future hold? What will ours be like?

I have been told that when you go through a life-shattering experience such as this, normal is what is happening at the time, so I embarked on a voyage of discovery. I could not find much written about hepatitis C. I was steered to organizations for help but was told by them they have nothing written on children with the disease. I realized I was about to become a pioneer. I was also forced to be doctor, nurse, lawyer, accountant, politician, detective, activist and mother. I have had to learn about what took place and why, and have had to fight very hard for Jarad's care and his rights. Every day brings something new. A call, a question, a court date, an obstacle. I live in my office, spend hours on the Internet and hours on the telephone. My days are long, there is no time off, not even on weekends.

The lack of information about hepatitis C has been the biggest hurdle we have had to overcome. The quality of information is also a problem, with some of the recog-

nized credible sources contradicting each other. Hepatitis C was only named in 1990, although it has been around for many years. The various issues involved with hepatitis C and the speed with which the disease is emerging, all combine to create a full-time job for anyone wishing to stay on top of it. This, as I see it, is my job!!

Unfortunately, there is no vaccination to prevent getting infected with hepatitis C, no medication for afflicted children to take, and no cure for it. It is a chronic degenerative disease that strikes and causes debilitating fatigue, nausea and headaches, at least in our son. All children should attend school, yet mine cannot. He does not have the physical strength nor the stamina to make it through a day.

I am most unhappy with the health care available for a child infected with hepatitis C. Health care causes more frustration for us, and other families, as we seek out someone who can stop the pain, take away the symptoms and restore a child's life to normal. After all, doctors are supposed to make the sick well. But no one is tracking the children. No one is testing for viral load or genotype. We have been told that biopsy, done routinely in adults to determine the degree of liver damage, would be a waste of taxpayer money in children. I am even more saddened by doctors who pull away citing the “complexity of his condition and the high level of technical expertise his care will require in the future.” Jarad has hepatitis C – he may require a transplant.

Jarad is somewhat of a ‘celebrity’, so acquaintances are plentiful. Unfortunately for him, real friends do not stick around. Children cannot fathom chronic illness. Their parents are afraid. Children get

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impatient when Jarad cannot play right now because he is feeling sick. They question why he takes many rest breaks and cannot keep up with their energy levels. Children do not understand why there is not simply a pill he can take that will make him all better.

I have become a 'teacher' – a childhood dream of mine, except that I do not do it in the classroom and do not collect a wage for what I do. I teach about hepatitis C in children, share our experiences and my knowledge all over North America. Thanks to hepatitis C, I have got to travel to places I never dreamed I would go. I have been asked to speak in Toronto, Regina, Calgary, Vancouver, Victoria, New York, Washington, DC, Houston, Texas and San Francisco, California. This summer, Jarad has been invited to meet Paul Newman and attend the Hepatitis C camp Newman is sponsoring in upstate New York.

This virus, despite how much I hate it, has brought with it good as well as bad. I have been fortunate to meet many fabulous

people who are as committed to education, awareness and prevention as I am. I have been forced to learn about politics and am bitterly disappointed with most of the knowledge that I have gained. I have viewed giving and greed. I have seen much pain and sorrow.

There is no way money can ever begin to make up for my son's life, for his suffering to date, nor his suffering in the future. There is no way compensation will begin to cover what this disease has already cost us financially, let alone what it has or will cost us emotionally, in the future. Money will never give Jarad a fair crack at life, restore his childhood or give him a normal adulthood. It will not prevent nor make up for the comments and discrimination that Jarad will face in the future.

As a family, we have already been forced to declare personal bankruptcy. We now have only one vehicle, our accommodation is now rental, our furniture is 19 years old and in need of serious repair, savings have been used up, the RRSPs are cashed and taxes paid on them, it has been 15 years

since we last went on vacation, the toys are broken and the trinkets gone. Health is not great – parents are stressed and tired, Dad suffers from depression, we live from paycheck to paycheck and we are all learning to live with what we have!

In order to assist families with liver disease going through similar situations, I recently incorporated the Children's Liver Alliance Canada Inc. This allows me and others to share our knowledge and experience. Our board expertise covers three vital areas: pediatric liver disease that children are born with; pediatric liver disease that is acquired; and bereavement. We are an international grassroots organization that offers the one-on-one peer support and guidance that families need most.

If there is a lesson that hepatitis C has taught me, it is that children are a gift to be cherished, loved, held, stroked and cuddled. And not just as babies – I take time out for all three, every day. And I never take life for granted – you never know when it will be gone.