

# When the unthinkable happens to your child

*The fear of critical illness striking a child is a common bond among parents. For these three Okanagan families the threat became reality. Now they're sharing their experiences in the hope that what they've learned may be of help—should the unthinkable happen to you.*

*Story and Photos by Laurie Carter*

## **The Nightmare Begins**

**Jarad Gibbenhuck** was born on July 17, 1988. He wasn't a healthy baby, but there was no specific indication of the cause. Then his heart failed. At just eight weeks, the tiny boy underwent the emergency open-heart surgery and blood transfusion that saved his life—and plunged his family into the vortex.

"He never recovered fully as expected," explains his mother, Leslie. "It was totally unnerving." The doctors, having no other explanation, simply labeled his condition as "a failure to thrive." As any mother would, Leslie took their pronouncement personally. "What am I doing wrong?" she wondered.

As time passed, Jarad caught everything – not unusual for a child with two older siblings. But

with Jarad, a simple cold would turn into pneumonia and he'd be rushed to hospital. Often Jarad's tummy would feel sick and he'd refuse to eat. "He had no energy," Leslie recalls. "He'd start to climb the stairs and fall asleep halfway up. The fatigue factor was incredible."

Yet doctors could find no answers. Through seven years and more than 400 medical appointments, Leslie persisted. One doctor finally suggested a psychiatrist—for her—reasoning that she was the one with the problem. The breakthrough didn't come until February 1995.

By chance, Leslie heard a blurb on TV warning that children who had received blood transfusions at BC Children's Hospital between certain dates should be tested for HIV. Although Jarad fit the criteria, the Penticton family didn't really expect this to prove anything because Jarad had already been through so many tests. But they went ahead.

"One month before his seventh birthday, we got the good news/bad news call," says Leslie. "Jarad was not HIV positive—what he had was Hepatitis C." Over the phone, with no opportunity for counseling or even compassion, she learned that the disease is a virus that attacks the liver and that it can be fatal. Hepatitis C is the primary reason behind liver transplants.

**Sophia Pratico** started life on October 2, 1998. Though a little under weight, she appeared healthy enough. But within four hours of arriving home, Sophia stopped breathing. Parents Sharon and Bryan rushed her to Emergency and in a whirl, the tiny bundle was on an air ambulance to BC Children's Hospital. The terrified parents had to follow on a commercial flight.

After closed heart surgery to repair the two defects pediatric cardiologists had found, Sophia

recovered and returned home to Vernon. "But within weeks she was showing signs again," says Sharon. Then she crashed. "It was always an emergency," says Bryan of the family's second trip to Vancouver. This time the result was open-heart surgery.

By August Sophia had stopped gaining weight and her energy was very low. "When she was one year old, she couldn't sit up by herself, much less walk," Sharon recalls. At thirteen months they got the news. "There was nothing else they could do," says Bryan. "She needed a transplant."

**Dustin Burnham** was 14 the day he came home from a baseball game complaining of a sore throat. His mother Leaza took a look and found strange blisters in his mouth and throat. She set up a doctor's appointment. But when the doctor examined Dustin the next day, the blisters were gone.

Although the teen's blood pressure had risen sharply, the Kelowna family was told not to worry, that it would run its course. "We were dumb enough not to get a second opinion at that time because we didn't realize how serious it was," says Dustin's father, Robb. The blood pressure continued to rise and being untreated, got so bad Dustin wound up in Emergency.

Treatment had no effect. Finally doctors realized Dustin's kidneys were starting to fail, though they still didn't know why. Apparently his symptoms were characteristic of several diseases. There were numerous trips to BC Children's Hospital—once on an emergency air evacuation—but still no answers.

Treatment included various drugs and ultimately, even though the Burnhams had resisted it as long as possible, chemotherapy. "Over the years all we could do was maintain him," says Leaza,

"and watch him deteriorate."

In April 1999, disaster struck. "Total renal failure," recalls Robb. "By then we knew he needed a transplant."

### Treatment

The day **Jarad** was diagnosed with Hepatitis C "we went out to get information," says Leslie Gibbenhuck as she reaches into a file and pulls out three slim pamphlets. At the time, there was nothing else available. Now she points to a large filing cabinet and two floor-to-ceiling bookcases crammed with binders, books and videos.

Doctors advised that they keep Jarad's condition to themselves. "But as a family we decided we had to tell people," she says. "We couldn't take a chance on him giving it to someone else." Hepatitis C is acquired through direct contact with blood and possibly with bodily fluids. The most common transmission occurs via IV drug use, though sharing razors, toothbrushes, tattooing and body piercing are also known risks.

That's why the disease is very rare among children. But Jarad was one of the unfortunate victims of the infamous tainted blood transfusions. Now 11 years old, his medical records, from one hospital alone, fill a five-inch-deep box.

There is no cure, and the standard treatments, including chemotherapy, are harsh.

"We're not willing to put him through that now," says his mom, adding that they have sought every possible alternative. Diet, vitamin supplements, acupuncture, massage therapy and naturopaths are all on the list.

Then, early this summer, Jarad had a crisis. Just weeks before he was scheduled to attend a Paul Newman summer camp, he became very sick. "He would vomit 50 times a day," Leslie says. He couldn't keep anything down. They tried prescriptions, but nothing worked. For 13 days the boy lay, with his bucket, curled in the fetal position in front of the TV. He lost weight, grew weaker and took on a greenish colour.

"I was dying inside, too," Leslie recalls. "It hurt so bad to watch him." Frantically, she begged his

doctor, a specialist at the University of Alberta transplant centre, for any solution. There was a new drug — but because it was still experimental, it would not be covered by insurance. Price tag — \$1,200 for one-month's treatment.

Despite community fund raisers, the Gibbenhucks had already been forced to declare personal bankruptcy because of the costs associated with Jarad's illness. "Nothing is worse as a parent than not having \$1,200—knowing this is here and not being able to get it," says Leslie. Yet the family found a way and Jarad responded dramatically. He got his trip to camp and "was so thrilled with the experience."

For little heart patient **Sophia**, events progressed much more rapidly. Just two months into her second year of life, the little girl was already something of a media star. Hearing of the family's situation, the people of Vernon had rallied to their cause. "Sophia became Vernon's baby," says Sharon.

When the Praticos gathered up Sophia and her brother Gabe, to head for Toronto's Hospital for Sick Children, the whole town was behind them. "We packed up the house and everything we needed for an indefinite stay," Sharon remembers. "It was December. I think we had

three family Christmas dinners before we left."

In Toronto, they moved into Ronald McDonald House. According to Sharon, "that was like Dorothy landing in OZ." Another bonus was the news, following Sophia's medical examination, that she had far less lung damage than anticipated. "I knew she was being looked after by a higher power," says her mom.

The Praticos set about trying to live some kind of life while they endured what was expected to be a protracted wait. In the emotionally-charged business of infant heart transplants, Christmas is a bad time. There aren't many accidents or drownings to make organs available.

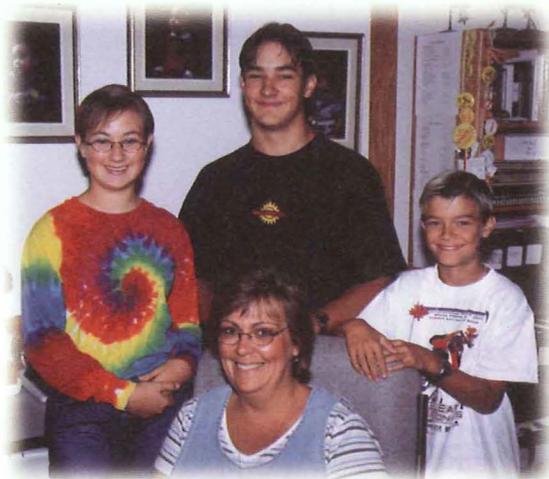
On December 23, Sharon returned from doing some last minute shopping. About 9 pm, the family was sitting around in their pyjamas when a message came through on the pager. Since they didn't recognize the name, Sharon and Bryan thought it might be a reporter who had managed to get the number. With no particular expectation, Sharon returned the call.

"Are you Sophia's mom?" asked the voice on the phone. Sharon said yes. "We have a heart for Sophia."

"I was standing up," Sharon recalls, "and I fell down."



The Praticos: Sharon, Gabe and cousins with Sophia in front



The Gibbenhucks: Ashley, Tyler, Jarad, seated - Leslie



The Burnhams: Taylor, Leaza, Dustin, Nana (Dianne Jaheny), Robb

Yet the moment was bittersweet. "Our first thought," says Bryan, "when we knew the heart was available, was—My God, someone lost their child at Christmas. It was just horrid." Sharon nods sadly at the memory. "We both started crying for that other family."

But there wasn't much time for regrets. By 8 am the next morning, Sophia was in surgery. Seven hours later she was resting in intensive care. Almost immediately the little girl started eating, gaining weight—and getting mad. With the constant monitoring of her vital signs, "she'd see a nurse walk in with that (blood pressure) cuff and she'd lose it," says Bryan.

In just two weeks, she was out of hospital. Of course, the follow-up treatment will continue all her life. Periodic biopsies are the only way to tell if a heart is being rejected. Sophia has had one major rejection episode. "That was really scary," says Bryan. "But she's done well since then."

For **Dustin**, the ordeal was just beginning. Although his kidneys were in bad shape, the family hoped that he could get along for some time without the need for dialysis. But he crashed. "Suddenly he's in surgery for peritoneal dialysis," recalls Leaza.

Robb explains that this is a procedure to install the apparatus so that the kidney patient can do a form of dialysis at home. For Dustin, the interim measure didn't work well. Within months he was rushed to hospital for three days of continuous treatment.

The scars on his arm are like the needle tracks of a junkie. When the peritoneal dialysis failed to work, he had to be fitted up for the more oner-

ous hemo-dialysis. This is the familiar treatment that connects the patient to a machine for hours at a time.

"It was working," says Leaza, "but it was so hard on the rest of him. He was sleeping 24 hours. He'd go to that, then come home and go to bed. He had no life—no energy."

The immediate family started the protracted process of being tested for tissue compatibility. Since people have two kidneys, it's possible to do transplants from living donors. In addition, the success rate from live versus cadaveric transplants is better. But among Leaza, Robb and younger brother Taylor there was not a match.

Enter grandmother, Dianne Jaheny, known to the family as Nana. The 10-year cancer survivor proved a willing match. On January 10 of this year, the 60-year-old and the 18-year-old prepared for surgery.

At the renal clinic of St. Paul's Hospital in Vancouver, Tuesday is transplant day. In a pair of operations that's actually tougher on the donor than the recipient, one of Dianne's kidneys was harvested then implanted in her grandson's abdomen. With kidney transplants, the old organs are not removed. The new kidney is simply added and hooked up.

Dustin's new kidney worked immediately. "In the recovery room he had nice pink colour," Leaza remembers. "He hadn't had colour for so long."

Though Dustin had to remain some weeks in Vancouver for regular hospital follow-ups, both he and Dianne recovered in record time. Dianne was told to expect a six-month convalescence. She was back to her job within four. Dustin took only three.

Like little Sophia, Dustin will continue to face the specter of organ rejection. Every week he goes to the lab for blood tests. "Fridays are always interesting," says Robb, in a tight voice. We happen to be talking on a Friday morning and the whole family turns to check the clock. Another hour before the results are in.

Dustin has also had numerous biopsies. His dad explains that the transplant patient wouldn't feel he was in rejection until it was too late. The biopsies are the only sure way to know if the anti-rejection medications are working. At first he was taking 56 pills a day. Now his mom estimates it's 25. "I don't count," says Dustin.

The average transplanted kidney lasts 10 to 15 years, though some are still functioning after 30. The Burnhams remain hopeful that technological advances will prevent Dustin from needing another donor.

### **Impact**

**Jarad** hasn't been able to attend school since the early primary grades. A teacher comes to his home for an hour and a half on school days, which is all he can manage before lack of concentration and fatigue set in.

Since he learned of his Hepatitis C, at the age of seven, he has insisted on treating his own cuts

and scrapes because he's so fearful of infecting someone he loves. As an 11-year-old, he regrets not being able to get his ear pierced and he wonders if a girl will ever want to marry him or if he'll be able to be a father.

Despite his youth, he's become an activist and travels with his mother, speaking on the cause of Hepatitis C. He's even written an enormously touching piece on life as a child with the disease. It's been turned into a pamphlet distributed by the Children's Liver Alliance Canada Inc.

Jarad doesn't live what any of us would consider a normal life, and neither does his family. "Going through something like this can't help but affect the family," says his mother, Leslie. "It's brought us closer together." But it's been far from smooth sailing, especially in the seven years before Jarad's condition was diagnosed. When a sudden flare-up would force the cancellation of family plans, it was very disappointing for older siblings Ashley and Tyler.

However, "once they knew why and could understand, it led to a whole new level of tolerance and understanding," says Leslie. Sometimes they get jealous because Jarad gets to travel, or because he doesn't go to school or gets gifts from people. But she makes a special effort to spend one-on-one time with them. "They get love and attention," she says. "All in all, they're better kids for it—wiser to the ways of the world."

And what of the parents? Jarad's dad, Pete, is always there when he's needed. But Leslie says it's very hard on him. Pete's the kind of guy who "if you can't fix it, it's hard to accept," she explains. Because he can't fix it, it's too painful, so he distances himself to cope and survive, she adds.

Leslie has taken the opposite approach. She manages to bury her frustration and anger in advocacy. Since Jarad can't go to school, she stays at home and works from her office next to the kitchen for the cause of liver disease. She runs support groups, writes articles, handles calls and E-mails, sends out information packages and speaks to groups all over North America.

"If I ever shut off the chat lines or message boards I might miss something that would help a whole lot of people," Leslie says. "I can't take that chance. I couldn't cope with this illness if I sat back and did nothing."

For **Sharon and Bryan Pratico**, one of the most profound elements of the experience of Sophia's heart transplant has been the reaction of the community. "Amazing and unbelievable don't even begin to describe how overwhelmed we felt by the support, prayers and good wishes," says Sharon.

The couple also feels a bond with other parents in the same situation. They keep in touch with those they met in Toronto and through the transplant society. "Sophia's doing so well," says Sharon. "Then you hear bad news from one of the others. It brings you back to reality."

Not surprisingly, the Praticos are passionate advocates for organ donation. They willingly cooperate with the media and give people access

### **Advice From the Parents**

#### *Leslie Gibbenhuck*

Educate yourself about your child's condition—you have to learn as much as you can.

Be your child's advocate.

Fight to the end—never give up.

#### *Sharon and Bryan Pratico*

Don't take your kids for granted.

Tell them you love them—hug them.

Don't ever give up.

#### *Leaza and Robb Burnham*

Get support from people who have been through it.

Get as much information as you can.

Get second and third opinions—don't worry about anybody's personal feelings. This is your child.

Never ease up on the pressure—it's the only way you can accomplish what needs to be done.

Do your best to keep up family life.

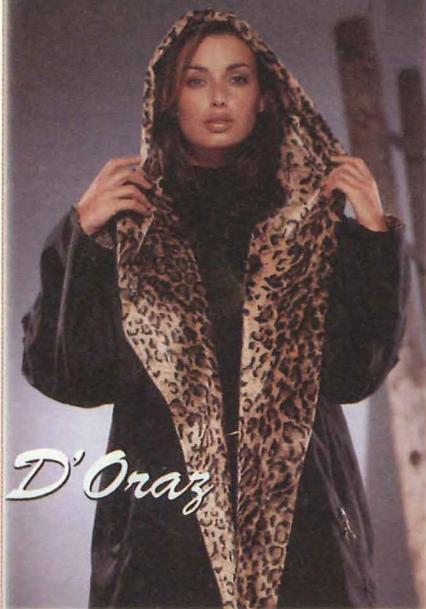
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to Sophia so they can see how precious a gift each of us has to offer. It's given Gabe a chance to have a little sister.

For now they take life one day at a time. "When she was sick, before the transplant," says Bryan, "we didn't know where the road would lead. Now it's rocky, but at least there is a road."

"To start it was a dead-end road," Sharon adds, picking up the metaphor.

"Now," says Bryan, "we look at this as all bonus. It's all extra."

For **Dustin**, being older when his illness struck, the experience has been very hard. "It's crap," he says. "It's the worst time to get sick, your teenage years. Look at my brother, how tall he is. It's horrible not being able to go to school. I didn't get good grades."

Leaza and Robb nod their agreement. Early on, Dustin was a real handful. He couldn't understand why this was happening to him and he needed somebody to blame. His parents took the hit. "That was so draining," says his mom, "'cause you just wanted to hug him. But when he was like that he didn't let us touch him."

It was also tough for younger brother Taylor. "It was pretty hard because most of the family was gone all the time," he says, referring to the frequent emergency trips to the hospital. "I was just worried because I didn't know what was happening."

"It was so frightening for him. The kid was only 12," says Leaza. "We tried to make sure we told him as much as he needed to know. When we didn't tell him enough, he got mad and let us know. After that we told him everything."

Now that the worst is over, the Burnhams are also becoming fervent donor advocates. Dianne has already been volunteering and Robb says the family "plans to map out our own little campaign. We're waiting until Dustin settles down."

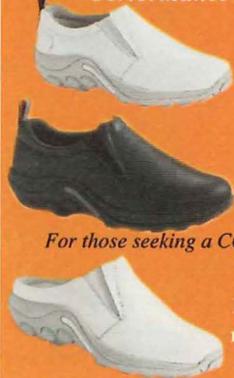
"We're just starting to breathe again," says Leaza. "Just trying to have a normal life again and not worry so much."

Dustin has enrolled in college and is studying media production with a long-term view to get in front of the camera.

Right now, more than 580 British Columbians are waiting for transplants. ■

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Phone (604) 877-2100

Web: [www.transplant.bc.ca](http://www.transplant.bc.ca)

Note: To register as an organ donor in BC you must complete a special registration form available on-line, at doctors' offices, pharmacies and ICBC. The old program of driver's licence stickers is no longer valid.