

Meet CHEO's Champion Child



It only takes moments and you are captivated by Billie Jo Decarie's personality. Sweet, kind, and friendly are only a few ways to describe her. She is also very mature for her thirteen years, a maturity born of a struggle with a serious illness.

Born on June 19, 1989 Billie Jo was HIV positive. By the age of six months she had full blown AIDS. She contracted the disease from her mother who had received a blood transfusion. Billie Jo has fought many battles during her life but has beaten the odds each time. Her parents were told that their daughter would never live to see age four but Billie Jo is a living testament to great medical care, a loving family, and a strong will.

As an infant, Billie Jo caught pneumocystis pneumonia which almost killed her. This pneumonia was a signal that she had AIDS because only people whose immune systems are compromised catch this particular form of pneumonia. She fought and won that battle but it would not be an easy road. "She has been an experiment from the beginning because she has been using difficult drug therapies. We've always been a step ahead of the technology and treatments for children," explains her dad, Bill.

Having a weaker immune system is tough for a child. Most children can bounce back from chicken pox, mumps, or measles but if Billie Jo were to catch any of these childhood conditions there could be grave consequences. When a classmate is diagnosed with one of these conditions the school principle contacts Billie Jo's parents. They immediately take Billie Jo to CHEO to get an injection into her knee to help fight against these particular ailments.

Over the years Billie Jo has been a frequent patient at CHEO. She has been hospitalized many times and has had many adverse reactions to her drug therapies. Regardless of this, her spirits are up and she continues to be an advocate, locally and nationally, for HIV awareness and safer blood for Canada.

Billie Jo's positive attitude is a direct reflection of her parents. They have always been open and upfront with her concerning her disease. "Before she was old enough to understand, her mom Johanne and I would explain that she had bad blood," says Mr. Decarie.

Not only is Billie Jo fighting to help others understand HIV/AIDS, she is also an advocate for CHEO. Billie Jo has been chosen to be the 2003 CHEO Champion Child to represent the thousands of children and youth that visit CHEO every year. Children are chosen from each province across Canada for the Foresters Champions Across Canada

Program. “It’s like a dream come true to be the Champion Child,” she says. When asked about her care at the hospital she replied, “Everyone is always there for me.” Billie Jo has been involved with the Foundation in the past as well. She has been the patient rep for the Dream of a Lifetime Lottery, volunteered her time on the phones during the Telethon, and even does her own external fundraising. In her mother’s hometown, Hammond, the community members have a yearly activity day in which all proceeds are designated to the HIV clinic at CHEO. Last year’s total was a whopping \$24,000.

Billie Jo now only visits CHEO once a month for IV gamma globulin treatments. She just recently learned that she will have an operation in March because her stomach isn’t healing properly after her feeding tube was removed. That was disappointing news but she continues to beat the odds and take things one day at a time.