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Cerebral Palsy

Darlene had her two boys at a fairly young age. Her boys were born 15 months apart. When she was four months pregnant with her second son Jacob, Darlene was involved in a car accident. She was stuck between the steering wheel and the car door. The emergency services personnel had to use advanced life saving techniques including the jaws-of-life to get her out of the vehicle. Darlene suffered multiple traumatic injuries including a broken forearm, kneecap and foot. It was a miracle that she did not miscarry, but was able to carry her Jacob to full term. Darlene's eldest child Jeremy was also in the vehicle. Jeremy was 11 months old at the time of the accident, and he suffered severe head trauma.

Darlene's children were of average weight and length at birth. According to the doctor Jeremy grew normally for a baby. Jacob also started normal by the doctor's description. But by the time Jacob was six months of age, Darlene realized that Jacob was no longer normal; small things started to appear, such as not being able to sit on his own, nor was he even trying to start to crawl, and he had stopped gaining weight. She then decided to take her concerns to her family doctor, to which he responded, "We cannot do any testing on your son till he is a year old."

During this time, Jeremy was still under the care of a pediatrician who provided post traumatic care for head injury patients. During a routine appointment for Jeremy, the pediatrician inquired as to the health of Jacob. The

pediatrician noticed Jacob's failure to thrive. Darlene informed the pediatrician that she noticed that Jacob was not progressing like other children. Darlene addressed her concerns with her family doctor. The family doctor was still not willing to conduct any test on Jacob at that point. Darlene wasn't sure what was wrong with Jacob, but she knew something was not right. The pediatrician decided to go ahead and do the testing on Jacob to see if Darlene's concerns were valid. Upon completion of the multiple tests the pediatrician ordered, he diagnosed Jacob with Cerebral Palsy (CP) The pediatrician then explained how the diagnosis would proceed and informed Darlene of the various treatments for Jacob.

The pediatrician informed Darlene that Jacob would continue to undergo a number of tests for CP. The tests, as Raranawongsa states involve blood and urine analysis, to see if there are any hormonal, chemical or metabolic problems with the patient, he adds that an "Electroencephalography (*EEG*) is a measure of brain waves to help in the evaluation of brain function". (*emedicine health Raranawongsa, Boosara, MD, subheading- exams and tests, paragraph 2.*). Curtis and Rea state that a "Computed Tomography Scan (*cat scan*) uses X-rays to make detailed pictures of structures inside of the body," they also add that an "Magnetic Resonance Imaging (*MRI*) is a test that uses a magnetic field and pulses of radio wave energy to make three dimensional picture of organs and structures inside the body," (*BC health guild, Curtis, Jeannette & Rea, Caroline*).

Jacob went through numerous trials, and tribulations, for at the age of

fourteen months of age before a diagnosis was made. Finally Darlene had the answer to her burning question, "what is wrong with my son?". The pediatrician explained, "that her son had CP with the complications of cerebral atrophy" (which is partial brain death) and then gave Jacob a life expectancy of only five years.

Shortly after his diagnosis Darlene was referred to the Shriners, through an independent source. As with most children with CP, Jacob's growth and motor functions were affected. In order to receive necessary tests and surgeries the Shriners would bus them down to Portland, Oregon twice a year for the first few years after being accepted as a Shriners' child, and once a year towards the end of his life for testing and surgeries. The surgeries consisted of tendon stretching, *tendon stretching involved cutting and casting so his tendons would stretch to keep his legs straight.* If not for this surgery Jacob would have been like a cross legged ballerina. He went through this surgery twice more. First to extend for the groin tendons, Jacob had this operation multiple times. The second surgery was to extend the Achilles and hamstring tendons. During this surgery Jacob underwent a third groin tendon extension. After these surgeries he was in a half of a body cast for six weeks each time. In addition of the surgical procedures in Portland, Jacob also underwent extensive testing at Children's Hospital in Vancouver and Queen Alexandria in Victoria.

In 1997 Jacob underwent another surgery. This surgery was to insert a gastro-intestinal feeding tube. Jacob was showing signs of anorexia. At this time

of this surgery Jacob was only 22 pounds. After the surgery and having the feeding tube inserted his weight increased steadily until he reached 50 pounds. Jacob's doctor felt, it would be healthy for Jacob to be heavier than 50 pounds. In 2004 Jacob was diagnosed with scoliosis and hip dysplasia .Jacob would have had to undergo an operation to correct his hip Dysplasia by his 20th birthday. Jacob passed away from multiple organ failure and complication of Pneumonia six weeks before his 19th birthday. Over the years there were a lot of people in Jacob's life that helped Jacob cope with his many challenges. Susan a registered nurse from Community Health Living acted as the go between, Jacob's family and the Doctors, and Anne from Family and Child Services helped them set up the "At home program", (which is a program that helps parents with disabled children get funding from the government) as well as therapeutic riding, product distribution (for his supplies), swimming and put us in touch with Louise, Darlene's respite care giver,(is a person who helps parents, by taking the child for a couple of days, so the parents may have a rest and rejuvenate themselves), for the last 8 years of his life. When Jacob was 18 months old he started at the Child Development Center and continued there until he started Kindergarten at Cumberland Elementary School at age 5. Jacob continued to attend school at Cumberland Elementary School until age 15 at which time he transferred to Mark Isfeld at Mark R. Isfeld Senior Secondary School Jacob took part in the life skills program (which is a program set up by the school district to help prepare the challenged individuals with the life skills needed for the outside world of their parents home and school life after they graduate from school). Jacob continued

his education in the life skills program until his death in February 2008. He would have graduated in June of 2008.

Even through all of his diagnosis and various treatments, Jacob was a joy to be around. Darlene learned a lot about patience and love from him. Jacob had a smile for everyone he met. For such a small guy he had a lot of strength and you could tell that from when he hugged you and would not let go until he was ready. He was loved by all and will be missed by everyone that he knew, especially by his mom and stepdad, his brother, his grandparents and his godparents and his extended family and friends.

Submitted by Darlene Sanders