Anna Van Giesen
Fort Worth, Texas

"*From the day you are told your child has cancer, you life is never the same,"* Anna's mother reflected a number of times after her daughter was diagnosed with neuroblastoma, a rare form of childhood cancer.

In 1989, Anna Van Giesen, a charming, active 3 year old began to limp. After a series of doctor's visits, resulting in a bone scan, the diagnosis was made. Rarely found early because the symptoms are not visible, this form of cancer is usually only discovered when it has metastasized, as was the case here. The primary tumor was the size of a baseball. At the time of the diagnosis, the family was told that without treatment, Anna would not live more than two months. In less than a month, this aggressive cancer had spread throughout Anna's body. Even if treated aggressively, the family was told at the time that the survival rate was usually less than two years. However the chances for survival improved with a then, new advance form of treatment, an autologous bone marrow transplant. Fortunately one of only 20 pediatric cancer centers in the United States at that time was at Cook- Fort Worth Children's Hospital, in Anna's home town. Further, this hospital was only one of three that was performing a high level purge of the immune system, a high level treatment for neuroblastoma.

Anna was actively in treatment from September 1989 until May 1990. She received rigorous treatment, everything that was available at the time and in extremely high doses.

First she was given toxic doses of chemotherapy to reduce the size of the tumor. In April 1990, the tumor, then the size of an egg, was removed from Anna's pelvis followed by harvesting her bone marrow. Next, a combination of near lethal doses of chemotherapy and radiation were given to kill all the cancer in her body. This included intense chemo therapy for three days followed by intense radiation for the next three days. With her immune system basically destroyed, Anna had an autologous bone marrow transplant. Her own harvested bone marrow, that had been purged, was reinjected and her body began to regenerate new marrow. In the course of this part of her treatment, Anna was in isolation for six weeks.

Along with the treatment, this spirited little girl had shingles, a bleed out that was nearly fatal and celebrated her 4th birthday in the bone marrow transplant unit. During the sudden bleed out, the medical staff was able to sustain her life by continual infusions of blood platelets provided by friends as well as unknown donors. She also had periods of complete fatigue. When Anna's energy was totally depleted, she and her mom would spend five hours having a blood transfusion which gave her the fuel to continue to fight her disease and to enjoy being a little girl. These transfusions were necessary approximately once a month during the nine month treatment. An intravenous line was implanted in Anna's chest to receive chemotherapy and other necessary fluids.

Of the group of twelve children treated during that period of time at Cook's Children's hospital in Fort Worth, Texas, Anna was the only one who survived childhood. In the year from September 1989 to September 1990, Anna was in the hospital 25 times but she never lost her spirit. At the age of 4 she became involved in dancing. Her mother was determined that Anna

not grow up feeling handicapped and spent many long hours making life as normal as possible for Anna and her older sister Sara.

Although Sara could not be with Anna during those long weeks, the sisters visited daily through the window of the bone marrow unit and by telephone. Sara stood on the balcony outside the unit where Anna could see her and talk to her on a direct line but not have physical contact for fear of infection.

The treatment was not without side effects. Anna hearing is limited and she is dealing with other side effects of both radiation and blood transfusions but today she remains cancer free and at 22 is about to graduate from college.

Anna's mother, Marge, definitively says that there is no way that Anna would have survived the treatment without the blood and/or platelet transfusions when she had the major bleed during the difficult days of the bone marrow transplant. Nor would she have been able live through the nine tedious months of treatment without the regular transfusions.

For informational purposes, this treatment is no longer used because it is so difficult on the body.

Additional Notes

Neuroblastoma is the most common form of childhood cancer. A cancer of the sympathetic nervous system, a nerve network throughout the body that carries messages from the brain, neuroblastoma is a solid, malignant tumor that manifests itself as a lump or mass in the abdomen or around the spinal cord in the chest, neck, or pelvis. It is often present at birth, but is not usually diagnosed until much later when the child begins to show symptoms of the disease. Most are discovered before the children is 2 years old and they are virtually never found in children older that 10. Treatment for this frequently fatal disease has improved over the last few decades but survival, particular without immediate and full treatment is limited.

The common forms of treatment are for neuroblastoma are

- Surgery.
- Radiation therapy
- Chemotherapy.
- Bone marrow transplantation**.**

The side effects of many of the above treatments are often sever and require blood transfusions for survival.

The majority of survivors have long-term effects from the treatment. These can include hearing loss, growth reduction, learning difficulties, and greater risk of other diseases.

Some facts:

- The average age at diagnosis is two
- Neuroblastoma has one of the lowest survival rates of all pediatric cancers
- It accounts for 8% of all childhood cancer but 15% of all childhood deaths.
- The survival rate of high risk children is 30% at the best
- There is no known cause or cure[1]

About 25% of newly diagnosed neuroblastomas are found in children under the age of one Children under the age of one have a cure rate as high as 90% [2], [3]

[1] Children's Neuroblastoma Cancer Foundation
[2] http://www.acor.org/ped-onc/diseases/neuro.html
[3] http://www.medicinenet.com/neuroblastoma/page3.htm