

## ***The Owen Lea Story***

In October, 2003 - just two weeks after his second birthday - Owen was hospitalized for a severe bone infection in his leg. After two weeks of being non-responsive to antibiotics, a chest x-ray was done to rule out pneumonia. A large mass was found in his chest and a biopsy confirmed one of every parent's worst nightmares. Owen was diagnosed with stage IV

*Neuroblastoma* - a very rare and difficult to treat form of childhood cancer.

had

Further exams showed that the cancer spread to his pelvis, his head, and also his bone marrow. The prognosis was not good, and the odds were overwhelmingly against him.



After five rounds of almost the most harsh chemotherapy a body can take, Owen underwent surgery

in March,

2004 to remove what was left of the

tumor in his chest. Amazingly, the small mass that the surgeon removed was nothing but scar tissue. The tumor had completely died. The cancer had also disappeared from his head, and a biopsy showed no evidence of disease left in his bone marrow. Our son had beaten the odds and was well on his way to a complete recovery. In April, he was checked into the bone marrow transplant unit at MCV Hospital in Richmond for a stem cell transplant, to ensure any lingering but undetectable cancer cells that may have been left in his marrow were dead. After a week of hard chemo, Owen's stem cells (which had been harvested from himself in November of 2003) were infused back into him to rebuild his immune system and replace his bone marrow. After three weeks of inpatient with no complications, he was discharged to spend the remainder of his recovery at home. As a precaution, radiation was done in July and August to his head and chest, where the majority of the cancer had been located. In September of 2004, Owen started preschool as a normal, healthy three year old boy. He was in complete remission.



Neuroblastoma has a high rate of relapse, so that thought was continually hanging over our heads. Despite this constant fear, we had slowly settled back into a normal family routine. In June of 2005, after being in remission for about a year, those fears were realized when a sizeable tumor showed up on a routine CT. A follow-up MRI confirmed the dreaded feeling that had overcome us. Owen had relapsed. He once again began a regimen of chemo and radiation, after surgery to remove the tumor. A biopsy had confirmed that the cancer had also returned to his marrow, and we were facing even worse odds than we were at the initial diagnosis. But Owen surpassed all expectations and beat the odds once again. In November, of 2005, he was once again cancer free. Knowing this time that the odds of the cancer staying away were far too high to simply do nothing, we started researching clinical trials and settled on an immunotherapy trial at *Memorial Sloan Kettering Cancer Center* in New York City. The first trip to New York was nothing short of awe inspiring. The atmosphere of the clinic was truly unbelievable and the optimism of the medical team nearly overwhelmed us. In February of 2006, Owen began the *3F8 monoclonal antibody protocol*. The treatment was extremely painful, as the antibodies they inject attach to nerve endings in the entire body. But Owen performed like a champ and was able to receive two rounds of the treatment before his body developed a normal immunity towards the medicine. Once again, he was off treatment, and this time we could only sit back hope that it would work.



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In the Fall of 2006, a small spot was detected on his leg. A quick blast of radiation and light chemo managed to clean him up, but once again we realized that despite the success of the treatment to kill the cancer, keeping it from coming back was going to continue to be the real challenge. In the Spring of 2007, the cancer once again returned in Owen's head. He was placed on another trial in New York that specifically targets Neuroblastoma in the head and brain.

Unfortunately, Owen was the only child out of the 10 that had previously undergone the treatment that was ineffective on. However, through more surgery and radiation, Owen was once again back in remission - for the fourth time.

In the Fall of 2007, the cancer once again returned, and once again, in his head. We were getting to the point where he could no longer have any more radiation to the same area of head without permanent damage, but fortunately the new tumor was in a spot that had not had any previous disease. So once again Owen had radiation and surgery to remove the cancer. He was back in remission for the fifth time.

Owen's fifth relapse came in the Spring of 2008, when a sizable tumor was found on his jaw. After a few more rounds of chemo, a routine bone marrow biopsy showed that the cancer had spread to his entire body. At this point we thought it was the beginning of the end, but amazingly, after two rounds of hard chemo and numerous rounds of a lighter protocol, he once again beat the odds. By Halloween, Owen was cancer free for the sixth time.



December of 2008 is when the tide started to turn for the worse. New cancer had once again appeared in Owen's head, at a spot that had already seen too much radiation. However, MCV Hospital in Richmond had a new type of highly focalized radiation that did less damage to the surrounding tissue. The neurology team in Richmond were convinced that they could blast the spot with only one round, instead of the 12 that is usually required for Neuroblastoma. Owen's seventh remission came late in 2008, when the stereotactic radiotherapy did its job. Unfortunately, we realized it was to be short lived when in February, more spots appeared on the opposite side of his head. Once again, the specialized radiation did the trick, but not without consequences. The areas of the brain where the radiation had been done had started to have a fluid build-up. The side effects were bad, and Owen started having seizures. We were able to control them with medicine, but they got steadily worse over the next few months and Owen eventually lost partial use of the left side of his body. Even though we were assured that he would more than likely make a full recovery with the proper physical therapy, we could tell that Owen was becoming less and less the happy little boy who always tackled his problems with a smile, but more the grown up boy who was finally able to start understanding what was happening to his body,

and starting to question why. In late July of 2009, after a normal day of fun and smiles, Owen suffered yet another seizure and was rushed to the emergency room in Richmond in the middle of the night. Two days later we learned that a new tumor had grown near his brainstem and this time it was inoperable.



On the 26<sup>th</sup> of August, 2009, at 2:35 in the morning, Owen Scott Lea left our world for a better place. It was only then that we truly realized how many lives he had touched. The Owen Lea Foundation was founded to continue this fight - if not for our little boy, but for others. We are determined to do everything possible to ensure that someday no other family will ever have to suffer the pain of watching their child fight this horrible disease. Please help us in our fight and make Owen and Waffie proud!