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*Dedicated to improving
diagnosis, treatment, and
quality of life for people with
von Hippel-Lindau disease*

For Immediate Release- May 10, 2006

May is VHL Awareness Month

Derik Hodges: A Young Warrior Against VHL Disease



Derik Hodges is a 12 year-old boy who lives with his parents, Ann and Scott, in Newington, CT. He loves going to school, hanging out with his friends, and joining them on class trips. One of his favorite playmates of all is his dog, Percy. He exhibits a near adeptness in the art of kenpo karate, and looks forward to getting his green belt. Everything points to Derik being a normal 7th grader except one thing: he suffers from Von Hippel-Lindau disease, a rare tumor-causing disorder for which there is no cure.

Von Hippel-Lindau disease is non-discriminatory. It can strike people of any race or national origin, anywhere in the world. It is the result of a genetic mutation that can afflict entire families, as it can be passed from either parent to one or all of their children. Without early detection of the tumors it causes -- tumors that can occur in multiple locations throughout the body -- the disease is often crippling and sometimes fatal.

During the month of May, VHL Awareness Month, we put forth an additional effort toward informing the public about this potentially debilitating disease. It is still considered rare, as approximately 1 in 32,000 are affected, and its onset is a cunning one, often difficult to identify. What helps doctors to diagnose new cases are previous diagnoses of VHL in the family. 80% of patients with VHL have family members who suffer from its effects. Unfortunately, the remaining cases are the result of spontaneous genetic mutation, and are the first incidence of the disease in their families. Derik is one of those cases.

Derik's Story

Derik was only ten years old when his symptoms began: he was vomiting daily and suffering from serious headaches. After nearly two years of numerous visits to different doctors, and a series of misdiagnoses, an MRI discovered the presence of a brain tumor in Derik's cerebellum, the region located at the base of the brain that governs movement. He would require surgery to remove the tumor or he would die.

Derik and his parents were told that a compromised or damaged cerebellum could result in serious balance issues, and that he might be forced to use a wheelchair, a feeding tube, and a ventilator for the rest of his life. They decided in favor of the surgery in an effort to save his life.

Remembering the doctor's warning, Ann prayed for her son through the long surgery, but accepted that the worst could occur. Instead, early the next morning, much to the shock and surprise of the nurses, the neurosurgeon, and Ann, Derik was awake and breathing without a respirator. With the help of his mother and a nurse, he walked to the bathroom by himself, just hours after his complicated brain surgery was completed.

The neurosurgeon examined the tumor and realized that the hemangioblastoma they removed was indicative of VHL disease. They are making every effort to treat Derik right now. He has already had another surgery to remove a tumor from his retina, and he will need another to remove a lesion from his cervical spine.

Derik continues to fight. He is back in school already, and looks forward to making a full recovery from his brain surgery so he can go on class trips again and use his new mountain bike. Someday, this young animal lover even hopes to be a veterinarian. But he also understands the importance of getting funding for research so that a cure can be discovered. He is a true young warrior against his disease, working toward living a full and exciting, disease-free life.

Derik wants to raise \$5,000 for the VHL Cancer Research Fund. He needs your help to do so. He is selling VHL bracelets to raise awareness and funds for the cause. He continues to work with his mother toward finding venues where he can plead his important case to others. If you want to help Derik reach his target, as well as others by donating to the quest for a VHL cure, please go to <http://firstgiving.com/Derik>

For more information about VHL, see www.vhl.org or call 800-767-4845.

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