

## VHL Family Alliance

### PRESS ANNOUNCEMENT:

BOSTON, Dec. 13, 2010 – The second episode in a three-part series on Grey's Anatomy features a patient with von Hippel-Lindau disease (VHL). The next new episode in the show is expected to air on January 6. The first episode, "Adrift and at Peace" aired Dec. 2 (<http://tinyurl.com/vhlstory1>).

VHL is a rare disease, a genetic cancer syndrome that causes a series of tumors in many different parts of the body. It is hard to diagnose, but getting a diagnosis is not the end of the story. In the Dec. 2 Grey's Anatomy episode, a man with von Hippel-Lindau disease is diagnosed with a "dangerous tumor of the adrenal gland," called a pheochromocytoma, or "pheo" for short. Pheos are dangerous because they emit bursts of adrenaline at random intervals. When they do, it feels like a panic attack that causes your heart to race and your blood pressure to rise. This can cause a heart attack or stroke. If it operates like that at a lower level, over time it can cause heart disease. At Seattle Grace (Grey's fictional hospital), the doctors seem to understand that the pheo needs to be removed, but this patient has maxed out his insurance. Future episodes will reveal how the story of this von Hippel-Lindau patient unfolds.

More information about VHL is available from the VHL Family Alliance at <http://vhl.org>. The VHL Family Alliance, founded in 1993, brings together patients, their families and friends, and physicians and researchers in a coalition to learn about VHL and provide information to patients and physicians on the best ways to diagnose and treat this disease. There is still no cure, but there is greatly improved management, allowing most people with VHL to live happy and productive lives.

"This organization does a fantastic job of informing its members, providing clinicians with critical information which is essential since the condition is rare and most doctors are unfamiliar with its diagnosis and management," says Dr. Michael Gorin, Jules Stein Eye Institute, UCLA Medical Center, a medical advisor to VHLFA. "Though small and with limited funds, the VHLFA has encouraged dialogue and collaboration among research groups working on the disease and has helped to support clinical research studies ... No other organization with which I have worked (and I deal with many) has used its resources so wisely and to accomplish so much for those who need help."

Joyce Graff of the VHL Family Alliance commented, "It takes knowledge, attention, and most important, access to care and teamwork with the doctors. What we need most of all is a cure. The clues to curing common diseases lie in the rare diseases. Studying VHL is leading to new therapies for cancer. A cure for VHL will be a powerful tool in many kinds of cancer."

To support the VHL Family Alliance in its effort to achieve a cure for von Hippel-Lindau disease, visit <http://vhl.org> or call 800-767-4VHL. Or go to <http://www.facebook.com/vhlfa>

Note to media: People with VHL in your own region are available for follow-up human interest stories.

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