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FOR IMMEDIATE RELEASE

May 2008 is declared as Awareness Month for von Hippel-Lindau (VHL)

Boston, Mass., May 1, 2008 – The VHL Family Alliance (VHLFA) has declared May 2008 as "VHL Awareness Month" in an effort to increase awareness, education and communication about von Hippel-Lindau (VHL), a genetic condition involving the abnormal growth of blood vessels in some parts of the body which are particularly rich in blood vessels. VHL is caused by a flaw in one gene, the VHL gene, on the short arm of chromosome 3, which regulates cell growth. The condition can cause cysts or tumors to grow in numerous parts of the body including, but not limited to: eyes, brain, spine, liver, kidneys, and adrenal glands.

Impacting about 1 out of every 32,000 births, VHL is often passed through a family, from parents to children, however approximately 20% of VHL cases are new mutations. The condition knows no racial or geographic boundaries, impacting people in every corner of the globe. While most cysts or tumors manifest in a person's teens or twenties, some people develop issues before age 10, while others do not show any signs until their 80's.

The VHL Family Alliance was founded 15 years ago to provide a resource repository for people and families with VHL, information for members of the medical community and fund research to improve the quality of life for those with VHL and, ultimately, to find a cure! The VHL Family Alliance is a national charitable 501 (c)(3) non-profit organization with local and state chapters throughout the country. As well, a system of international VHL affiliate organizations allows for great information and resource sharing, research coordination and communication.

Until a cure is found, VHL patients should work with members of their medical team to undergo regular screening including CT scans and MRI's to watch for tumors before they become problematic. Like diabetes, there is no cure for VHL, but with medical advances in screening and research, the future looks brighter for VHL patients and families.

The May 2008 "VHL Awareness Month" campaign will include outreach to elected officials to educate about the impacts of their decisions on the VHL community, outreach and education to the medical community, and a targeted opportunity for the media to shine a light on VHL and the amazing people that are living their lives with this condition.

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