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FOR IMMEDIATE RELEASE

VHL Family Alliance Fosters Strategic Partnerships

Boston, Mass., May 19, 2008 – Finding a cure for von Hippel-Lindau (VHL) and funding research cannot be done in a vacuum. The VHL Family Alliance (VHLFA) has taken a strategic and deliberative view when it comes to working with other organizations, companies and associations in promoting research, providing education and resource sharing to further the improvement of quality of life for VHL patients and families, while seeking the cure for VHL.

The VHLFA has developed strategic partnerships with such organizations as the Genetic Alliance, a national non-profit organization that serves as a coalition of more than 600 advocacy organizations serving 25 million people affected by 1000 conditions. The organization works to transform leadership in the genetics community to build capacity in advocacy organizations and to educate policymakers by leveraging the voices of individuals and families.

As well, the VHLFA has partnered with the National Organization for Rare Diseases (NORD). NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

The VHLFA has partnered with the National Research Disease Interchange (NDRI) as a host for the VHL Tissue Bank. NDRI was founded in 1980 by its president, Lee Ducat, a Philadelphia mother of a diabetic child. As a non-profit corporation funded primarily by the National Institutes of Health, NDRI is dedicated to the procurement, preservation, and distribution of human cells, tissues, and organs to researchers studying over 100 diseases. VHL Family Alliance will be working with NDRI's Rare Disease Initiative, which is exploring new ways to help scientists find the biomaterials they need to better understand and treat so called "orphan" or rare diseases.

The VHLFA works with countless other organizations and institutions in an effort to promote education and awareness, raise funds and find a cure!

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