

VHL Family Alliance Announced Partner in Rare Disease Day

VHLFA is holding local event; a dinner in honor of Rare Disease Day on February 26th in the Coolidge Corner/Brookline area

BOSTON, Mass., Feb. 5 (SEND2PRESS NEWSWIRE) – The National Organization for Rare Disorders (NORD) is coordinating the observance of Rare Disease Day in the United States on February 28, 2009. VHL Family Alliance announced today that on that day, and in the weeks leading up to it, they will join with others around the world in focusing on rare disease challenges and the importance of research in developing diagnostics and treatments.

Joyce Graff, the executive director of the VHL Family Alliance (VHLFA), has been a board member of NORD for almost 10 years and is currently working with her staff and members to participate in this event. VHLFA serves people dealing with vascular tumors of the eye, brain, spinal cord, kidney, pancreas, and adrenal glands. These and other tumors occur in a condition called von Hippel-Lindau disease (VHL). Graff says, "VHL affects one person in 32,000. But there are more than 7,000 rare diseases. Each of the rare diseases may be rare, but the experience of having a rare disease is not rare. One person in ten is dealing with some rare disease."

The VHL Family Alliance (VHLFA) will be posting news about this upcoming event on its website (www.vhl.org) and is actively encouraging its members to write essays and post videos sharing their experiences with VHL. An article about Rare Disease Day is in VHLFA's January newsletter.

According to Graff, "Those of us with VHL have many issues in common with other rare diseases – the difficulty of getting a diagnosis, or finding appropriate treatment, the stresses of living with a long-term condition, the worries about what may happen to your children." Graff hopes that Rare Disease Day will help to raise awareness of rare diseases and the need for safe, timely diagnosis, and effective treatment.

Along with other NORD partners, VHLFA is holding its own local event – a dinner in honor of Rare Disease Day on February 26th in the Coolidge Corner/Brookline area. For tickets and more information, call 1-800-767-4VHL.

Nord welcomes anyone with any medical challenge or rare disease at rarediseases.inspire.com or www.rarediseases.org.

About Von Hippel-Lindau Disease

VHL is a risk factor for a number of tumors, caused by a tiny misspelling in one copy of one gene, the VHL gene. People who carry this flaw are at increased risk for tumors of the retina, brain, spinal cord, kidneys, pancreas, and adrenal glands.

About VHL Family alliance

VHLFA is a non-profit organization that provides information for families and physicians about this disorder and local self-help support groups for families affected with VHL. It is dedicated to improving diagnosis, treatment, and quality of life for individuals and families affected by Von Hippel-Lindau disease.

About NORD

The National Organization for Rare Disorders is 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.

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