

PRESS RELEASE

VHL Alliance and NORD Launch New International Databank

To Support Research and Gain a Better Understanding of VHL and other Forms of Cancer, Patients and Medical Experts Around the World will Share Critical Information in Search of a Cure!

BOSTON, May 14, 2014---The VHL Alliance, a nonprofit advocacy organization supporting patients and families affected by von Hippel-Lindau, has launched a new international databank aimed at better understanding this disease and other forms of cancer.

The new Cancer in our Genes International Patient (CGIP) Databank at www.vhl.org/databank will allow patients around the world to share relevant data, connect with researchers, and support research on how variables such as diet, exercise and even oral health may affect disease progression.

The VHL Alliance has created this databank in partnership with the National Organization for Rare Disorders (NORD), which represents all Americans with rare diseases. This is the **first** of many such disease-specific databanks that NORD will be creating.

"VHL Alliance is thrilled to partner with NORD in launching the Cancer in our Genes International Patient Databank. The CGIP will provide a complete 'picture' of each patient's experience with these diseases, making it possible to assess the effects of diet, exercise, environment and other variables," said Ilene Sussman, executive director of the VHL Alliance. "It will also provide a safe platform for patients and researchers to connect and confidentially exchange data in order to accelerate treatments and a cure."

NORD President and CEO Peter L. Saltonstall said VHL Alliance's databank provides what is widely recognized as one of the greatest needs of the rare disease community – natural history data to help medical researchers better understand how diseases develop and progress over time.

"We believe the CGIP is an important new resource for patients and researchers, and we look forward to offering use of our new platform to other rare disease patient organizations," Saltonstall said.

"Since VHL patients battle a series of tumors throughout their lives, they are an ideal population for studying tumor growth and identifying ways in which a patient's lifestyle or environment may affect the progression of the disease," says Sussman.

And, while von Hippel-Lindau disease is rare, the VHL gene is involved in many other forms of cancer. The new database will include data from patients with several other rare forms of genetic cancer, and could ultimately influence the treatment of many other types of cancer including common forms.

In forming this first-ever database, the VHL Alliance partnered with medical experts from around the world. In addition, the VHL Alliance and NORD consulted with the FDA on questionnaire design to help future development of promising therapies.

While only about 1 in 32,000 Americans have VHL, the disease has been featured on Grey's Anatomy. Also, "The Voice" recent contestant "Emily B" shared with the nation how she has been affected by this rare disease. In addition, best-selling author Tom Rath, who was diagnosed with VHL at age 16, has served as a vocal advocate for the patient community. His most recent book -- *Eat. Move. Sleep. How Small Choices Lead to Big Changes* -- was published in October 2013.

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ABOUT NORD

Established in 1983 by rare disease patient advocates, NORD represents the nearly 30 million Americans affected by rare diseases, their families, and the patient organizations that serve them. It provides programs of advocacy, education, research, and patient/family services to improve the lives of all people living with rare diseases. Learn more about NORD at www.rarediseases.org.



About The VHL Alliance

The VHL Alliance (VHLA), a 510(c)3 non-profit organization located on Boston was founded 1993, is the preeminent resource for VHL and related tumor conditions. The organization is an international network that provides education and support to more than 15,000 people in 108 countries and has affiliate support groups in 26 countries on six continents. To date, the VHL Alliance has awarded over \$1.4M in grants leading to advances in cancer research. The VHL gene is a primary player on the path of angiogenesis and thus is one of the keys to understanding cancer. For more information about VHL or VHLA, visit www.vhl.org.

