The VHL Alliance at a Glance

The VHL Alliance is dedicated to research, education, and support to improve awareness, diagnosis, treatment, and quality of life for those affected by VHL. The organization was founded as the VHL Family Alliance by two VHL caregivers and a VHL patient in 1993, the same year that the VHL gene was identified. Its mission was to connect and educate VHL patients and their families while providing information to healthcare providers to advance VHL diagnosis, treatment, and quality of life.

Over twenty-five years, the VHL Alliance has become the pre-eminent resource for patients, caregivers, researchers, and the medical community. It is part of an international network serving an estimated 15,000 people worldwide, in 108 countries.

In 2011, the organization underwent its first major leadership transition with the retirement of Founding Director Joyce Graff, and embarked on a strategic planning process which included reviewing the organization’s vision, mission, strategies, and tactics. The resulting blueprint was documented as a guide for the VHL Alliance. The Boston-based organization has a staff of four full-time employees. Members of its governing board include patients, families, and supporters from across the US.

The VHLA services its constituency in a wide range of areas:

**Medical research** is essential to achieving the VHL Alliance’s vision of discovering a cure for VHL; discoveries from VHL research have directly led to at least eight cancer drugs currently on the market. The **VHL Research Council** not only reviews and awards grant proposals, $2.3 million to date, but it also coordinates with the broader research community to move forward to finding a treatment and ultimately, a cure. In addition, the VHLA brings together leading VHL researchers and clinicians in a biennial **International VHL Medical/Research Symposium.** It has also initiated “**MyVHL: A Patient Natural History Study.”**

**Education** is the heart of empowering people with VHL and their families to make the best medical decision possible for their individual situation. Educating both healthcare providers and patients helps achieve the best outcome. The VHLA reaches its constituency through a number of tools, including newsletters, social media, and its vhl.org website. The **VHL Handbook** contains the most up-to-date information for diagnosing and treating VHL. The VHLA also reaches its constituency through a network of active volunteers, spearheaded by our Ambassadors working at the local and regional to welcome new constituents, reach out
to existing constituents, and build. The VHL Hotline, on-line support networks, and a number of regular telephone discussion groups provide further assistance to patients.

The Annual Family Weekend each fall brings patients, families, and clinicians together for a weekend packed with clinical education and lively discussions. The Julie Flynn Hope Retreat for Young Adults is an annual opportunity for younger patients to address their time-of-life specific concerns, and build community.

Support to improve awareness, diagnosis, and treatment for VHL patients starts with the Clinical Advisory Council, a team of physicians representing every clinical specialization related to VHL manifestations and care. The Council is tasked with developing the national and global network of Clinical Care Centers. Participating hospitals commit to coordinating, care across medical specialties, thereby improving diagnosis and treatment of VHL. Educating medical professionals about VHL diagnosis and treatment is essential for improving patient outcome. In addition, it is vital that healthcare professionals are up-to-date with the most recent approaches to VHL care. The “Von Hippel-Lindau Disease Spotlight” developed with Elsevier's Practice Update disseminates the latest research and information broadly across the medical community. Finally, Wellness Coaching seeks to address burnout caused by growing pressure on healthcare providers and caregivers. The combination of emotionally distraught patients and overworked healthcare professionals is likely to impact the important partnership essential for optimal diagnosis and continued care of patients with diseases such as VHL.

For more information about the VHLA or any of its programs, please see vhl.org, or contact Ilene Sussman, Executive Director, +1 617.277.5667.