



# VHL Family Alliance

*Dedicated to improving diagnosis, treatment, and quality of life for individuals and families affected by von Hippel-Lindau syndrome*

The VHL Family Alliance is a voluntary health membership organization comprised of patients, survivors, family members, physicians, researchers, and other health professionals.

The VHL Family Alliance was founded in 1993 by three families with VHL to share experiences, learn from one another, support one another, help the doctors solve this problem, and make life better for our children. We are now in touch with an estimated 14,000 people with VHL in 72 countries. We work to empower people to manage their health through

## INFORMATION, EDUCATION, AND RESEARCH

<b>What We Do</b>	We work to empower patients and their primary care physicians and health care teams to manage the health of the patients, doing their best job for the patient on the first try. We begin with the VHL Handbook, which is the only document in patient-accessible language that tells the whole story about VHL and constructive ways of living with VHL. We connect patients with others living with VHL, and answer questions for physicians, or field questions to appropriate experts.
<b>Who We Serve</b>	VHL affects approximately one in 32,000 people in every ethnic group, worldwide, which is approximately the same prevalence as muscular dystrophy. While it is most frequently inherited in families, 20% of the families are “new mutations” – an event that occurs randomly to a child in a family with no prior history of VHL. Once this change occurs, a child of an affected person has a 50% chance of having the condition. We serve families with VHL, people seeking a diagnoses, and physicians seeking current information about differential diagnosis, screening, and treatment options.
<b>Education</b>	There are five centers in the world where a significant amount of clinical research has been conducted with hundreds of patients for 20 or more years. It is not possible for all people with VHL to travel to one of these centers. In most cases, one doctor and one patient are learning about VHL together for the first time. Through the Handbook, a network of Clinical Care Centers, and an information Hotline, we work to spread this expert knowledge out to the field.
<b>Research</b>	The VHL gene, discovered in 1993, is basically a recipe for the VHL protein. When the normal supply of VHL protein is interrupted in a cell, the normal regulation of cell growth is also disrupted, which can kick off a process known as angiogenesis, the growth of new blood vessels. This is a normal process, gone out of control. It can lead to formation of a knot of unnecessary blood vessels, or one of a variety of tumors in different organ systems. It is this same process of angiogenesis which takes place in all cancers, and is necessary to fuel the growth of a cancer tumor. Research on VHL and the VHL protein are therefore keys to solving cancer for everyone, not only for people with this condition. By following the clues given by this condition, we are developing new strategies for dealing with cancer.
<b>Global Reach</b>	Through the internet, the website, online discussion groups in four languages, and affiliates in 14 countries worldwide, we learn with families and healthcare professionals in many different countries and medical cultures worldwide.