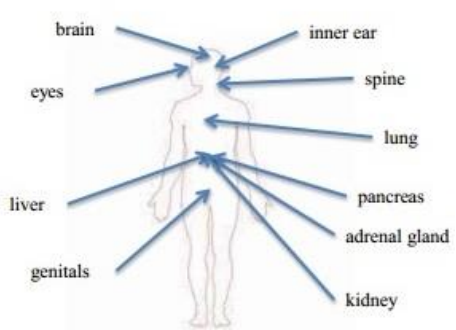
VHL Canada ● www.vhlcan.ca

VHL (von Hippel-Lindau) is a rare genetic disease and cancer syndrome that results in tumors growing in as many as 10 areas of the body. VHL is caused by a mutation in the VHL gene, which is supposed to suppress tumours. VHL, once diagnosed, requires lifelong screenings to provide early identification and diagnosis of non-cancerous and cancerous tumors, as well as intervention when necessary, which usually comes in the form of multiple surgeries.

- 80% are inherited and 20% are "new" cases
- Affected parents then have a 50% chance of passing it on to their children
- Most tumors are benign, but still can cause long-term and dangerous problems
- However, tumors in the kidney and pancreas can become malignant or cancer that can spread
- Because of the constant scanning and surgeries, VHL impacts the emotional and financial lives of patients. For example, a VHL patient can endure 3-15 surgeries in their life
- Treatment of tumours by drugs is not as effective generally
- About 900 Canadians have VHL (1 in 36,000)
- Average age of diagnosis is 26, but tumours can occur from childhood throughout adulthood
- VHL affects males and females equally, and all ethnic groups and countries

Where tumours grow



VHL Canada is a registered charitable organization
Our mission is to improve the lives of those affected by VHL in Canada
www.vhlcan.ca
2017 sources include: National Organization of Rare Disorders, Children's Hospital of Philadelphia, VHL Alliance (Boston) and Orphanet