Living with VHL

VHL disease is a lifelong condition. However, with appropriate measures, people can effectively manage the VHL and lead full and productive lives.

Early diagnosis, regular surveillance, appropriate treatment, emotional support, and living a healthy lifestyle are all keys to effectively managing the condition and reducing the negative impacts of any tumors or cysts.

Healthy Lifestyle

There are conscious decisions people can make every day to support their holistic wellbeing.

There are many factors that affect a person's health. Some things, like genes or age, cannot be controlled. Many things, like sleep, nutrition, and exercise can be controlled. A healthy lifestyle will help improve your overall health and well-being.

Be active and make time for regular exercise.

Choose healthy foods and a balanced diet. Consult a dietitian or nutritionist as needed.

Strive for balance in both personal and work life.

Make time for important relationships.

Ask for help (including emotional, physical, spiritual help) whenever support is needed.

Find healthy ways to relieve stress with things like relaxation techniques. Be open-minded and try a new hobby or activity.

Keep in mind that any lifestyle change is a "work in progress" and that lasting changes take time. Set small goals that are easy to accomplish. Positive psychology shows that the more times people meet their goals—

even small goals!—the more likely they will build confidence which enables them to accomplish more (and bigger) goals in the future.

It is important to live a healthy lifestyle, but being healthy means different things for different people. Certain diets might not be appropriate for individuals with VHL disease who have manifestations on the pancreas, adrenal glands, or kidneys. Strenuous exercise may not be appropriate for other people, especially during post-operative recovery periods. Doctors should be consulted before making any major lifestyle changes.

The <u>Patient Natural History Study</u> gives patients an opportunity to contribute to research which is investigating how lifestyle choices—like nutrition, exercise, and sleep patterns—can impact the overall health of people living with VHL. Please consider contributing to this important research!