

Key Issues for People Living with VHL in the US

Health insurance can be difficult for anyone to navigate. When you have VHL, it can be particularly tricky. Understanding and accessing your insurance plan benefits in order to obtain the care you need can be challenging. This guide is intended to outline some of the key points that VHL patients living in the US may wish to consider as they navigate decisions about health insurance.

Choosing a Plan

If the patient does not have group or employer health insurance, he/she can purchase health insurance on his/her state's Health Insurance Exchange. There are multiple plans available, allowing you to choose the plan best suited for your health requirements. If you need help navigating the options, you can contact customer service at your state's exchange. Alternatively, there are local health insurance agents and brokers who can help patients choose a plan. Most exchanges provide a listing of local agents and brokers. The open enrollment period begins November 1st and ends on January 31st for coverage for the following year (after December 15th, coverage will begin in February or March).

Plan choices are available for Medicare (usually ages 65+) and Medicaid (Medi-Cal). Medicare Advantage plans have a limited enrollment period (October 15th – December 7th) each year, with an exception for initial enrollment at a person's 65th birth month. Medicaid enrollment occurs once a person qualifies. Each state has individual procedures. For those with a child under age 18 with VHL, the child may qualify for CHIP health insurance from the state at reduced or no cost.

VHL patients who are US citizens and reside in California may qualify for GHPP, the Genetically Handicapped Persons Program. For more information about this program, please see the visit the GHPP webpage on California's state government website. You may also wish to contact the VHLA Chapter Leaders for California: us-ca@vhl.org.

"Medical Necessity"

A common challenge faced by VHL patients is a denial by their health insurance plan for a recommended screening test, procedure, or treatment. The reason for denial that insurer's give: lack of medical necessity. Generally, this occurs because the plan has limited understanding of VHL. Patients can work with their care team to educate the health insurance provider and demonstrate that it is in everyone's best interest to cover recommended screening tests, procedures, and treatments.

Insurance companies, as well as Medicaid/ Medi-Cal, and Medicare have guidelines in place for determining medical necessity. Each insurer may develop its own guidelines, follow the policies of their umbrella association (ex: Blue Cross Blue Shield), or contract with a company that creates utilization management guidelines. The claims reviewers deciding upon medical necessity for specific pre-authorizations or claims are often practice nurses working with a physician medical director. They are not experts in rare genetic diseases and may deny something that they do not understand.

Genetic Testing

Another health insurance coverage challenge is evaluation of blood relatives of diagnosed VHL patients. The American Society of Clinical Oncology (ASCO) identified VHL as a Group 1 disorder, a hereditary disease for which genetic testing is considered part of the standard management for at-risk family members (American Society of Clinical Oncology 2003). This means that diagnostic genetic testing of the VHL gene should be considered a standard of care for each person in whom VHL is suspected. If a VHL genetic mutation is identified, then each of their first-degree relatives (parents, siblings, and children) should be tested for that specific mutation. Ideally, a genetics professional—a genetic counselor or a clinical geneticist—should be involved in the genetic testing process by providing pre-test evaluation and counseling, test coordination, and post-test counseling.

Pre-Authorization and Claims Review

Insurance utilization managers and claims reviewers may not have any idea where to look for documentation to support pre-authorization or a claim outside of their standard guidelines. This means that the burden will fall to your physician. Before you have a test or a procedure, make sure your healthcare provider contacts the insurer for pre-authorization. If the insurance company balks, then the physician should write a letter of medical necessity providing a persuasive argument that the requested test, treatment, or procedure has important clinical utility—i.e., the results will cause a real change in care. Clinical practice guidelines, vetted by a national organization—like NCI (National Cancer Institute) or the AAP (American Academy of Pediatrics)—carry weight and should be cited in the letter of necessity as a way of convincing the reviewer that the request should be approved; not do so would mean failure to follow clinical standards, thus not allowing the physician to meet the legally required standard of care.

If the reviewer still refuses to authorize the test, treatment, or procedure, and your physician's arguments are strong, you can request, in writing, that the insurance company use an outside reviewer. You and your physician can also ask that that reviewer have certain qualifications, such as board certification in a particular specialty, such as Clinical Genetics or Neurosurgery. The health plan (including Medicare and Medicaid/Medi-Cal) must comply with these requests.

This can be tiresome and inefficient for you, your doctor, and your health insurer. However, this gives you the best chance to remove any barriers to obtaining the tests and treatments you need, and will allow you to manage your VHL disease according to the latest guidelines. Your efforts will also ease the way for other VHL patients with the same health plan to obtain approval for the care they need.

Other Resources

Examples of well-accepted national guidelines and reviews that may help persuade your health insurer of medical necessity include: USPTF (US Preventative Services Task Force) recommendations, NCCN (National Comprehensive Cancer Network) recommendations, or even GeneReviews. For example, here are the VHL recommendations from [GeneReviews](#). Other resources on health insurance coverage include:

- [Families USA](#)
- [Health Insurance protections by state](#)
- [Child Health Insurance Policy \(CHIP\)](#)
- [Medicaid and the Children's Health Insurance Program \(CHIP\) Compliance Programs](#)



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