



PATIENT
EDUCATION

VHL Patient Card

Name _____

MRN# _____

Provider _____

Center Phone: _____

I have VHL.

I may have a
pheochromocytoma.

If I have surgery, I may need
alpha (α) and beta (β)
blockers.

-OR-

I may have postoperative
adrenal insufficiency.



Possible symptoms of VHL lesions

Brain/Spinal Hemangioblastoma:

Headache, slurred speech, stumbling, back pain, hiccups, numbness, involuntary eye movements

Retinal (eye) Hemangioblastoma:

Floaters, flashers, retinal detachment

Endolymphatic Sac Tumor: Hearing loss, tinnitus (ringing in ears), vertigo

Pancreatic Cysts and Tumors:

Pancreatitis, diabetes, digestive problems, jaundice

Pheochromocytoma, Paraganglioma:

High blood pressure, panic attacks, postop adrenal insufficiency

Kidney Cysts and Tumors: Lower back pain, blood in urine, fatigue

Cystadenoma: Pain (consider rupture, hemorrhage, torsion (twisting))