



VHL Research Questionnaire

PART 1- Personal Information

Part 1 will be kept separately from the rest of the information; it will not be added to the database.

Personal Information

Date of entry (dd/mon/yy): ____/____/____ Date of Birth (dd/mon/yy): ____/____/____

First Name: _____ Last Name: _____

Last Name at birth (if different from above): _____

Address: _____
Street

_____ City State/ County Zip/ Post code

Home Phone: (____) _____ Email Address: _____@_____

I want to be informed about research results: Yes _____ No _____

Data from parts 2-7 will be added to the database

PART 2- General Questions

Year of Birth (dd/mon/yy): ____/____/____ Sex: _____

Ethnicity: _____
(e.g. White, Hispanic, Black or African-American, American Indian, Asian, Native Hawaiian/
Pacific Islander. If other or mixed, please specify _____)

Height: _____ Weight: _____

PART 3- Family History

1. Is your family affected by VHL? Yes _____ No _____ I don't know _____

2. Has the mutation in the VHL gene been found in your family? Yes _____ No _____

If yes, year of analysis? _____ Which laboratory? _____

3. Please fill in the table on your family history:

Family member	Who has VHL? (tested, confirmed)	Who does NOT have VHL (tested, confirmed)	Who might have VHL?	Unknown	Total number
Mother					
Father					
Brother(s)					
Sister(s)					
Son(s)					
Daughter(s)					
Grandfather					
Grandmother					
Uncle(s)					
Aunt(s)					
Cousin(s)					
Nephew(s)					
Niece(s)					

PART 4- Medical History

1. Age of first symptoms: _____ 2. Age when first diagnosed: _____

2A. What was the first feature identified? _____

3. Which clinical care center/ hospital/ nursing care facility is currently taking care of you?

What are the regular intervals of your screenings?

Twice a year: _____ Yearly: _____ every 2 years _____ others: _____

When were your last screenings? Year: _____

The current status of your vision:

	Good Vision	Partial Vision	Blind	Enucleated
Left Eye				
Right Eye				

The current state of your hearing:

	Good hearing	Partial hearing	Disturbance	No hearing
Left Ear				
Right Ear				

von Hippel-Lindau disease can have a variety of lesions. Please check as accurately as possible the lesions and/or cysts which apply to you. N/E stands for “not evaluated”, meaning you have not had screening for that body part. The word lesion is used to describe angiomas, hemangioblastomas, and tumors.

	Yes (Include number of tumors/ lesions/ cysts and year when diagnosed)	No	N/E not evalu- ated	Surgery (year)	Do you still have tumors/ lesions/ cysts? (If yes include number)	Other (please specify)
<u>Eyes:</u>						
Retinal lesions						
Left						
Right						
Retinal detachment						
<u>Brain:</u>						
Cerebellar lesions						
Brain stem lesions						
Other e.g. pituitary, supratentorial						
<u>Spinal Cord:</u>						
Lesions inside the cord						
Lesions outside the cord						
Syrinx						
Other						
<u>Kidneys:</u>						
Cysts left						
Cysts right						
Renal Cell Carcinoma						
Left						
Right						
<u>Pancreas:</u>						
Cysts						
Lesions						

	Yes (Include number of tumors/ lesions/ cysts and year when diagnosed)	No	N/E not evalu- ated	Surgery (year)	Do you still have tumors/ lesions/ cysts? (If yes include number)	Other (please specify)
<u>Adrenal Glands:</u> Lesions left Lesions right						
High blood pressure						
Extra-adrenal pheo(s)						
<u>Hearing changes:</u> Endolymphatic sac tumor						
Tinnitus (ringing in the ears)						
<u>Men only Epididymis:</u> Cystadenoma left Cystadenoma right						
<u>Women only-</u> In VHL there are benign tumors that can occur in the reproductive organs, which are very difficult to diagnose. Have you ever been told that you had a lesion, tumor, or mass in or near any of the following? If so, what action was taken if any?						
<u>Broad ligament:</u> Fallopian tubes						
Ovaries						
Uterus						

5. Other Issues:

OTHER medical problems you think may be related to VHL, please explain below.
