



Family Planning

If one parent has VHL, the couple has a 50% chance of passing on VHL to any child they have. Whether or not a child has VHL, they will be impacted by VHL because they have a parent with VHL. Additionally, VHL can impact reproductive health for both men and women with VHL.

VHL can cause tumors in the reproductive area for both men and women. These tumors, called cystadenomas, generally are not symptomatic or dangerous. Thus, the [Active Surveillance Guidelines](#) do not include special monitoring of the reproductive tract.

In some cases, these cystadenomas can block the flow of sperm, causing infertility for men with VHL. If the tumors are removed, fertility typically returns.

In women, these lesions are said to occur “near the broad ligament of the fallopian tube”. They are generally not problematic, but sometimes these lesions can be confused with ovarian cancer. If a woman with VHL is diagnosed with ovarian cancer, her doctor should definitely be informed about this differential diagnosis so she does not receive treatment for “cancer” that she does not actually have.

At this time, there is no clear answer as to whether pregnancy, long term use of hormonal birth control, hormone replacement therapy, or high doses of hormones used for procedures like in vitro fertilization can promote tumor growth for women with VHL. For this reason, it is especially important for a couple where the woman has VHL to discuss family planning with their medical team, understand risk factors, and discuss what might happen if tumors grow during pregnancy.

What is known is that a woman’s body is designed to grow during pregnancy! For example, she will develop an entirely new organ (the placenta) and blood vessels whether or not she has VHL. Generally speaking, doctors try to avoid surgeries during pregnancy, but sometimes it may still be necessary. Here are 4 very important points from the [Active Surveillance Guidelines](#) that are specifically for a pregnant woman with VHL.

- Have retinal checkups every 4-6 months to anticipate potentially more rapid progression of lesions.
- Test for pheochromocytomas early, mid, and again late pregnancy to ensure there is no active pheo during pregnancy or especially labor and delivery.
- During the 4th month of pregnancy, have an MRI—without contrast—to check on any known lesions of the brain and spine.
- If known retinal, brain, or spinal lesions, consider C-section.

It is important to make sure the obstetrician knows about VHL and is connected with the other VHL medical team members. A woman with VHL should be extra vigilant in monitoring symptoms and reporting anything unusual to her doctor. Pregnancy is accompanied by multiple changes in the body. While some are normal in any pregnancy, they can be of particular concern for someone with VHL.

To learn more about considerations and symptoms, visit pages 52-56 of the [VHL Handbook](#).