

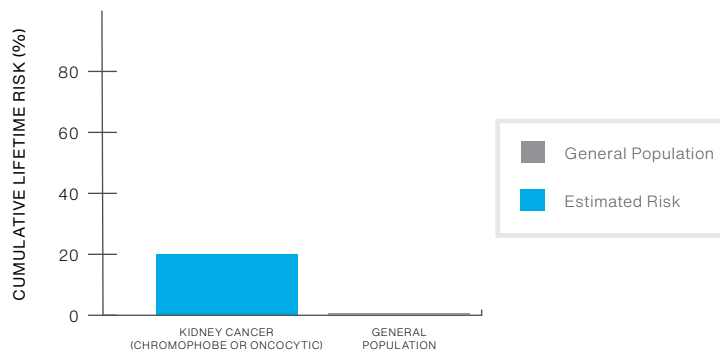
# Understanding Your Positive *FLCN* Genetic Test Result

INFORMATION FOR PATIENTS WITH A PATHOGENIC MUTATION OR VARIANT, LIKELY PATHOGENIC

## 5 Things to know

1	<i>FLCN</i> mutation	Your testing shows that you have a pathogenic mutation or a variant that is likely pathogenic in the <i>FLCN</i> gene.
2	Birt-Hogg-Dubé syndrome	People with <i>FLCN</i> mutations have Birt-Hogg-Dubé syndrome (BHDS).
3	Cancer risks and other medical concerns	You have an increased chance to develop kidney (renal) cancer and multiple benign (non-cancerous) skin tumors. You also have an increased chance to develop multiple lung cysts which can cause too much air to get in between the lung and chest wall, causing lung collapse (pneumothorax).
4	What you can do	Risk management decisions are very personal. There are options to detect cancer early or lower the risk to develop cancer. It is important to discuss these options with your healthcare provider and decide on a plan that works for you.
5	Family	Family members may also be at risk – they can be tested for the <i>FLCN</i> mutation that was found in you. It is recommended that you share this information with your family members so they can learn more and discuss with their healthcare providers.

## *FLCN* Mutation Lifetime Cancer Risks (%)\*



\* Because risk estimates vary in different studies, only approximate risks are given. Cancer risks will differ based on individual and family history.

## *FLCN* Mutations in the Family

There is a 50/50 random chance to pass on a *FLCN* mutation to each of your children. The image below shows that everyone can carry and pass on these mutations, regardless of their sex at birth.



## RESOURCES

- BHD Foundation [bhdsyndrome.org](http://bhdsyndrome.org)
- Genetic Information Nondiscrimination Act (GINA) [ginahelp.org](http://ginahelp.org)
- National Society of Genetic Counselors [nsgc.org](http://nsgc.org)
- Canadian Association of Genetic Counsellors [cagc-accg.ca](http://cagc-accg.ca)

Please discuss this information with your healthcare provider. The cancer genetics field is continuously evolving, so updates related to your *FLCN* result, medical recommendations, and/or potential treatments may be available over time. This information is not meant to replace a discussion with a healthcare provider, and should not be considered or interpreted as medical advice.