HLRCC FOUNDATION · GENETIC TESTING

Bring to your doctor

A checklist for a visit about FH (fumarate hydratase) genetic testing for HLRCC. Fill it in a few weeks ahead; relatives may need time to answer.

Your own health history

- [ ] Skin bumps (skin leiomyomas): where they are, when you first noticed them, and any biopsy result.
- [ ] Fibroids: your age when they were found, and any surgery, such as myomectomy or hysterectomy, with your age at the time.
- [ ] Kidney: any kidney tumor or kidney cancer, your age at diagnosis, and the pathology report if you have it.
- [ ] Copies of any past genetic test results, and your past kidney scan reports.
- [ ] Notes: _____

Your family health history

- [ ] For blood relatives on both sides (parents, brothers, sisters, children, grandparents, aunts, uncles and cousins): who had skin bumps, early or severe fibroids or a hysterectomy, or kidney cancer, and their age at diagnosis.
- [ ] A copy of any relative's genetic test report that names an FH variant.
- [ ] Notes: _____

Questions to ask

- [ ] Should I have FH genetic testing? Do I need to see a genetic counselor first?
- [ ] Which test and lab will you use, and will my insurance cover counseling and testing?
- [ ] If I test positive, which check-ups do I need, and when do they start?
- [ ] Who in my family should be tested, and at what age should my children be tested?
- [ ] Can I have a copy of my genetic test report?

Tip: consider bringing a family member or friend to help you remember what was said. Find a genetic counselor: findageneticcounselor.nsgc.org (in person or telehealth).

My name: _____ Visit date: _____

Doctor or genetic counselor: _____ Lab, if known: _____

Sources: NCI PDQ, Hereditary Leiomyomatosis and Renal Cell Cancer (2024); GeneReviews, FH Tumor Predisposition Syndrome (2025); NCI Genetic Testing for Inherited Cancer Risk; NSGC, What to Do Before Your Appointment; CDC, About Cascade Testing; HLRCC Handbook (October 2026). Full list: hlrcc.org/genetic-testing/#hgt-references

This checklist is educational and is not a substitute for advice from your own physician. Version: October 2026. hlrcc.org/genetic-testing/