



Tips for Individuals Newly Diagnosed with a Hereditary or Genetic Mutation

You or a loved one has been diagnosed with a hereditary or genetic mutation that increases the odds of cancer. While we understand it can be scary and overwhelming, we are here to help. This checklist will help you navigate this uncertain time.

- If one is not established for you, ask for a genetic counselor that can help explain the results and next steps. Genetic testing results and the implications are often difficult to interpret without guidance. If a genetic counselor is not available at your facility, please see the list of Hereditary Cancer Clinics (courtesy of Living LFS) in our resources section for a facility nearby. You may need a referral to visit a specialty clinic.
- Ask your genetic counselor for the full list of screenings or other treatment options that are recommended for your mutation. If you are currently in treatment, this list also could come from your oncologist or other specialist.
- The genetic results will become part of your medical record but it's important to inform your primary care provider (PCP) about the diagnosis apart from any active cancer treatment as they may be responsible for ordering future scans/tests and any referrals as noted above, especially if you have an HMO. If the PCP does not know the nature of your mutation, provide them with a copy of the list of scans you secured from your genetic counselor or doctor. Please also visit our resources section as we have tried to include websites for the various conditions caused by hereditary or genetic mutations, which can be shared with your PCP.
- Call your insurance to see if they have a case manager or similar type resource that can help you navigate at least the first year of your new diagnosis. If not, check with your medical group to see if there is someone who can provide more active help especially during the initial period.
- When you talk to the insurance company, confirm your deductibles, co-pays, and other requirements. Screenings often come at different intervals so it is possible to maximize your insurance benefits based on the screening schedule you choose.
- If the diagnosis is associated with a recommended course of action including surgery, consider whether a second opinion would make you more comfortable with your ultimate decision.
- The internet can be an important resource but as with all medical diagnoses, rely on your doctors and genetic counselors to provide the most relevant information. Hereditary and genetic mutations are often rare so statistics may be skewed. However, almost all mutations have support groups so we encourage you to look for one. Many are on Facebook or other social media platforms.
- While this is a life-changing diagnosis, after you have completed any treatment that may be associated with the discovery of the mutation much of what comes next focuses on prevention and early detection, not unlike the screenings recommended for the general population. People with hereditary or genetic mutations may initially face some preventative surgeries but often it's just a more aggressive screening schedule.

Do you have questions? We cannot give medical advice but will do our best to point you in the right direction – send us an email at danielle@hergen.org.