

PREPARE FOR YOUR APPOINTMENT AFTER YOUR EHE DIAGNOSIS

BEFORE YOU GO

- **Gain Basic EHE Knowledge:** Read the patient version of the *Consensus Paper: Guidance for Managing EHE*. Go to <https://fightehe.org/consensus-paper-guidance-for-managing-ehe/> or scan the QR code on the next page. Consider bringing a copy with you. Browse our website for information or to watch EHE 360 patient conference videos.
- **Plan your Questions:** Print these questions to bring with you, and write down any others specific to your symptoms or care. Prepare for your appointment just as you would for any important meeting, class, or other event. Don't forget to bring a pen, paper, and copies of any applicable records or reports.
- **Review Medications:** Make a list of current medications to bring with you. Include supplements, over-the-counter medications, previous medications that did not work, and any known allergies.
- **Plan to Bring Support:** If possible, plan to bring someone you trust, so they can help take notes and ask questions. Consider authorizing a second person to access your information with your provider.
- **Get Clarification:** As a patient with a one-in-a-million cancer, you will be your biggest advocate for your care. Contact The EHE Foundation's Patient Services Team at 1-877-460-4240 or patientservices@fightehe.org with any questions.

ASK YOUR DOCTOR

- **EHE Diagnosis:** Where was the tumor/biopsy sample analyzed? Did an expert pathologist review the sample to diagnose EHE? Is the diagnosis of EHE suspected or confirmed? Was any testing done on my tissue to determine if I have a gene fusion commonly seen in EHE? If so, what is that fusion? Is my EHE slow growing or advanced? Should I have more tests?
- **Scans:** Should I have additional scans to determine if EHE has spread to other parts of my body? How often should I have scans? Will different types of scans be on different schedules?
- **Tumors:** What are the sizes and locations of my tumors?
- **EHE Experience:** How many EHE patients have you treated in the past? This is especially important for an oncologist. *Don't hesitate to seek a second opinion or ask your doctor to consult with an EHE expert.* A Provider Directory is available on our website.
- **Treatment:** What are my treatment options?
 - Surgery:** Is surgery an option? What type of surgery? What should I expect in recovery? Would follow-up treatment be recommended?
 - Transplant (with liver involvement):** Is a transplant an option?
 - Chemo:** Is chemotherapy or other systemic or maintenance therapy a consideration?
 - Radiation, Ablation, or Embolization:** Should any of these be considered?
 - Watch and Wait:** If no treatment is advised, what is the active surveillance plan to monitor my tumors?
- **Patient Support Services:** What patient support services are available to me? Do you have a nurse navigator or social worker to help coordinate visits, tests, insurance appeals, etc.? What about psychosocial care, physical therapy, pain management, and palliative care (as applicable)?



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ONGOING

- **Electronic Medical Records:** Set up your electronic patient portal. Review the information that is reported about you, your treatments, scans, etc. Report any errors to your doctor.
- **Organize Your Records and Notes:** Print and store physical or digital copies of important documents such as your pathology reports, blood panels, treatment schedules, radiology reports, drugs, etc. Many patients find an organized binder or flash drive helpful.
- **Insurance:** Understand what is or may not be covered by your insurance policy. Some tests, treatments, etc may require prior-authorization. Confirm necessary authorizations have been obtained prior to appointments.
- **Stay Informed:** Sign up to receive information about potential treatments, research advances, and opportunities to get involved by subscribing to emails from The EHE Foundation at FightEHE.org. Be the best advocate for your care by reviewing valuable resources, such as articles, video recordings of patient conferences, and medical publications.

The EHE Foundation's mission is to find treatments and a cure for the this rare cancer by advancing research and driving collaboration between patients, researchers, and clinicians.



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