

EHE Foundation Biobank

PATIENTS POWERING RESEARCH

Patients living with EHE have the power to advance research by donating their tumor tissue or body fluid to the EHE Biobank. Research is the key to the development of new treatments, and biospecimens are essential to understand the disease and test new potential treatments. Because EHE is so rare, research is limited by the lack of available tissue.

The EHE Biobank is an open, ongoing collection of tissue and body fluids from people living with EHE. The Biobank also offers an opportunity for patients to leave a legacy by donating their tumor tissue postmortem.

The EHE Biobank preserves EHE biospecimens and makes them available to qualified researchers whose research has been reviewed for its science and the protection of the rights of those who donate.

DONATION IS EASY WE DO ALL THE WORK

Advanced planning is helpful in coordinating specimen donations. Please contact the Biobank Coordinator to discuss the Informed Consent and provide basic information about your EHE. We will then coordinate directly with your doctor.

CONTACT US

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YOU CAN ADVANCE RESEARCH

- If you are planning to have surgery, a transplant, or need to have fluid drained, contact the Biobank Coordinator as early as possible – even if you do not have a scheduled procedure.
- If you have had surgery to remove tumors in the past, there may be tissue stored at your hospital.
- Leave your legacy to the EHE community. Plan today for a posthumous tissue donation.

DOES DONATION AFFECT CARE?

Your donation to the biobank does not affect your care. This Biobank only requests excess tissue or fluid that is not needed for your medical care.

HOW WE PROTECT YOUR PRIVACY

We take your privacy very seriously. Your donated biospecimen and health information will be given a code number to protect your identity. No information directly identifying you will be provided to a researcher, only a unique code.