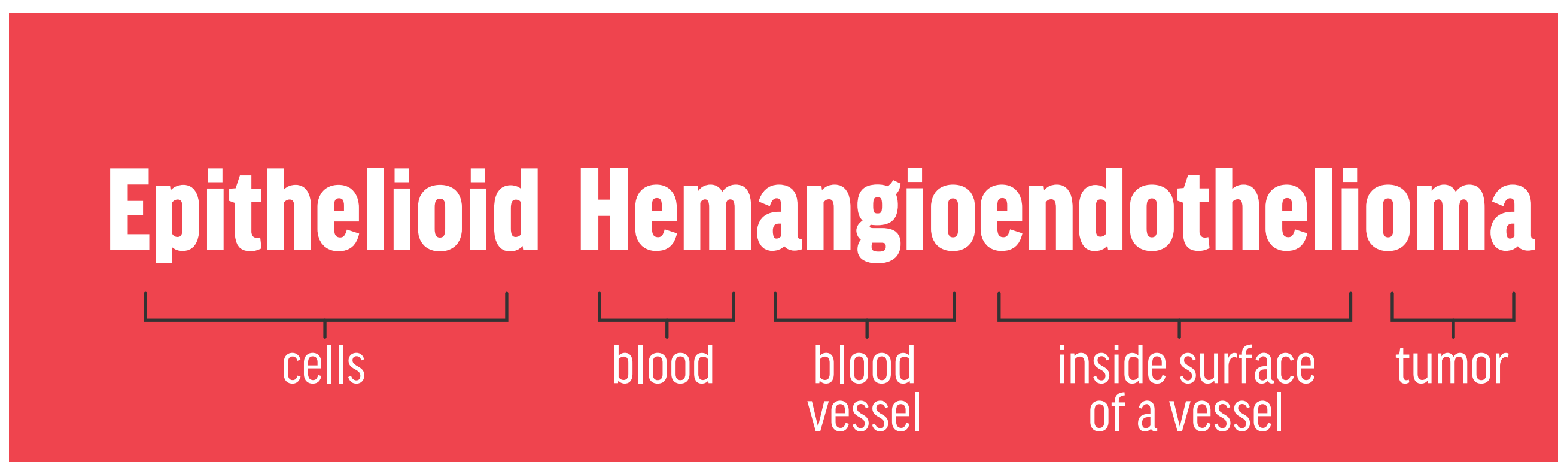
The EHE Foundation:
Patients Powering Rare Cancer Research

Denise Robinson, Director of Research, The EHE Foundation



OUR MISSION:

To find treatments and a cure for the rare cancer, Epithelioid Hemangioendothelioma (EHE), by advancing research and driving collaboration between patients, researchers, and clinicians.

What is EHE?

Epithelioid Hemangioendothelioma (EHE) is an ultra-rare vascular sarcoma that can occur anywhere in the body. It is estimated that less than 1 per million people are living with EHE. EHE most often appears in the liver, lungs, and bones and has a very unpredictable clinical course. There are currently no well-established standards of care or approved treatments.

Our Impact

- ***Supporting a global community of over 2,500***
- ***Connecting EHE patients, clinicians and researchers in 80 countries***
- ***Investing over $2.2M into critical research on EHE***

Learn More & Contact Us

Email: info@fightEHE.org
Socials: @EHEfoundation
Website: fightEHE.org

PATIENT-LED RESEARCH INITIATIVES

EHE Biobank

The biobank collects and preserves biospecimens in a central repository and makes them available to qualified researchers.

YOU CAN DONATE YOUR EHE TISSUE TO HELP
FIND A CURE FOR EHE

Tissue donated through the EHE Biobank allows researchers to develop living cell lines that can be used to idenitify treatments and eventually find a cure for EHE.

1. Visit FightEHE.org/ehe-biobank to learn more about how your tissue can help advance EHE research.
2. **Prior to any procedure**, contact the EHE Biobank Director to begin the process of consent and planning.
3. The EHE Biobank will work with your doctor and facility to coordinate tissue collection, at no cost to you.

Use this code to email us at ehebiobank@fightehe.org.

For more information, visit FightEHE.org/ehe-biobank or email us at ehebiobank@fightehe.org.

EHE Global Patient Registry

People diagnosed with EHE from anywhere in the world are encouraged to join and describe their experience with EHE over time.

EHE Global Patient Registry
EHEregistry.iamrare.

JOIN TODAY

EHE Research - Powered by YOU

You can participate in vital Epithelioid Hemangioendothelioma (EHE) research by joining the EHE Global Patient Registry and detailing your unique experience in a natural history study of EHE.

Because EHE is so incredibly rare, this is a powerful opportunity for you to ***directly impact EHE research*** to improve understanding of this ultra-rare cancer and accelerate research toward improved treatments and ultimately a cure.

Who can join the Registry?

Anyone diagnosed with EHE anywhere in the world, including:

- ✓ Adults
- ✓ Children or minors (represented by a parent or guardian)
- ✓ Deceased persons (included by a legal adult representative)

How to Join

1. Visit EHEregistry.iamrare.org to create your profile.
2. Consent to provide your information to the registry.
3. Answer questions about your EHE experience, such as symptoms, diagnosis and treatment.

JOIN TODAY
EHEregistry.iamrare.org

The EHE Global Patient Registry is hosted by the National Organization for Rare Disorders (NORD®) on the IAMRARE® secure platform, and is sponsored by The EHE Foundation, a 501(c)(3) organization dedicated to pursuing effective treatments for EHE and supporting patients and their families. To learn more visit **fightEHE.org**.

The EHE Foundation is grateful for the dedication of its Advisory Board, and to patients who have contributed to the advancement of EHE research.

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