



The EHE Foundation

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To find treatments and a cure for epithelioid hemangioendothelioma (EHE) by advancing research and driving collaboration between patients, researchers, and clinicians.

Epithelioid hemangioendothelioma (EHE) is an ultra-rare sarcoma affecting one in a million people worldwide, that can arise anywhere in the body with a high propensity for systemic involvement, occurring most prevalently in the liver, lungs, and bones. There are no approved treatments specifically for EHE, and options vary and are inconsistent around the world. Disease progression is unpredictable, and in many cases, the cancer progresses to an aggressive and fatal stage.



Left to right: Amy Baghdadi, Medha Deoras-Sutliff, Denise Robinson and Patty Cogswell, of the EHE Foundation, meet in-person at the Rare As One Network 2022 Meeting.

During the Grant Period

Impact Spotlight

With a vision of dramatically increased research in EHE, the EHE Foundation has laid the groundwork for such research through the development of foundational infrastructure and resources, including by rolling out a biobank in 2021, and initiating the development of a patient registry and a secure research forum for researchers and clinicians to connect, both in 2022.

In parallel, the foundation prioritizes and centers patients by engaging them with educational programming and research updates. By the end of the grant period, these engagement efforts — which spanned the globe — had led to a patient community more than 2,000-strong and spanning more than 70 countries.

Efforts to build a strong foundation and engaged patient community for research participation are — quite literally — paying off. In late 2021, the foundation announced receipt of a \$1 million, unrestricted gift from the Margie and Robert E. Peterson Foundation. With a strong patient community and research infrastructure in place, the foundation is poised to leverage these resources and more for research progress benefiting patients around the world.

Key research and research infrastructure achievements

- Organized two international conferences, institutionalizing 'EHE 360' as the leading global convening of the EHE community with the most recent event engaging 367 patient, clinician and research registrants from 13 countries.
- Launched the EHE Biobank, engaging 66 patients/ caregivers, consenting 41, and completing 25 specimen collections.

- Initiated the EHE Research Grants Program, awarding five grants.
- Partnered with xCures for an observational registry study, aimed at generating research for repurposing of an FDA-approved drug for EHE.
- Engaging in collaborative effort to create international clinical management guidelines.

Key publications

- *ESMO Open* (2021): consensus- and evidence-based best practices to approach primary and metastatic EHE, developed based on a global consensus meeting of more than 80 experts from across disciplines (co-authored by former Executive Director Medha Deoras-Sutliff).
- *Cancers* (2022): an evaluation of recent research and a framework for further investigating the biology of EHE and YAP/TAZ-dependent cancers (funded by the EHE Foundation).

Key operational achievements

Hired or contracted key roles including Executive Director, Director of Research, and Biobank Coordinator.

Key community achievements

Launched EHE Community Connections series, aimed at breaking down barriers and identifying critical needs of rare cancer patients living with EHE.

After the Grant

Since the grant period's end in January 2023, the EHE Foundation has experienced exponential growth in basic, translational, and clinical researchers engaging in the disease area and has had a significant maturation

of the organization's operational and research activities — serving its mission to find treatments and a cure for EHE. Achievements include:

- Expanded the collaborative research network to include over 150 sustained clinicians and basic scientists by May 2024.
- Initiated enrollment in the EHE Global Patient Registry, enrolling more than 200 participants from 24 countries by May 2024.
- Formed two new significant academic research partnerships.
- Distributed specimens from EHE Biobank for cell-line / EHE model development.
- Engaged in global drug repurposing initiatives, including stakeholders from US, EU, UK in meetings with regulators at FDA and EMA.
- Formed relationships with two industry partners initiating development projects focused on EHE.
- Supported efforts resulting in publications in *Frontiers in Oncology* and *Clinical Cancer Research* (1, 2).
- Implemented a CRM, capturing more than 3,500 constituents in more than 80 countries in 2023.
- Hired a full-time Executive Director and a full-time Director of Development and Communications, both in 2023.
- Initiated clinician and researcher newsletters.
- Strengthened partner alliance with European sister EHE organization.



The EHE Foundation's former Executive Director Medha Deoras-Sutliff (right) supports Board President Jenni Kovach (left), who was diagnosed with EHE in 2018.

“The EHE Foundation has experienced transformative growth in the past 3 years, significantly benefiting from the CZI grant and the organizational support and development investments gained as part of the Rare As One Network. Today, we are blazing trails toward our mission to find effective treatments and a cure for this ultra-rare cancer.”

Denise Robinson

Executive Director and Director of Research,
The EHE Foundation
