



SPONSORSHIP

A CALL TO SUPPORT
THE EHE FOUNDATION





OUR HISTORY

In 2015, patients and families living with EHE realized they were all facing the same challenges - EHE was often misdiagnosed, there were no treatments for the disease, and there was very little information known about it. Four women joined together and formed The EHE Foundation with the aim to find treatment options and to support people living with EHE.

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.

OUR VISION

A world where EHE is easily diagnosed and treatable.

WHAT IS EHE?

Epithelioid Hemangioendothelioma (EHE) is an ultra-rare vascular sarcoma that grows from the cells that make up the blood vessels and can occur anywhere in the body. It is estimated that less than 1 per million people are living with EHE, and the rate of new cases is estimated at 3.8 cases per 10,000,000 people per year.

EHE appears most often in the liver, lungs, and bones, and has a very unpredictable clinical course. EHE can be indolent with no signs or symptoms, have slow growth with mild symptoms, or be very aggressive with significant symptoms often including extensive pain. Overall survival varies widely depend on tumor location and progression.

There are no well-established standards of care or approved treatments for EHE. Because EHE is so rare, many doctors have no experience managing EHE patients, which often leads to misdiagnoses and misinformation.

OUR IMPACT

We celebrate our achieved progress and milestones, which are directly attributed to the support of EHE patients, their families and friends, advocates, clinicians, scientists, and researchers.

SUPPORTING

a global community of over

2,500

patients and advocates
in over 80 countries



INITIATING

critical
patient-led

RESEARCH

projects to better
understand
the disease



GRANTING

over

\$1.5M

to fund
EHE research

CONNECTING

expert clinicians with patients to
improve access to essential
multidisciplinary expert care



EMPOWERING

patients to advocate for their
own care by developing
comprehensive resources to
help patients and clinicians

FACILITATING

educational and
collaborative forums that
bring together patients,
clinicians and researchers

OUR INITIATIVES

Engaging clinicians, researchers and patients with programming and strategic initiatives designed to advance collaboration and education is critical to our primary objective to find a cure for EHE.

EHE 360: COLLABORATIVE RESEARCH

EHE 360 emerged in early 2020 as a global event that virtually united over 300 EHE stakeholders. Today, EHE 360 is not only an event to share research and clinical advancements, essential educational, and supportive information. EHE 360 is a movement that threads through all of our efforts and binds patients, researchers, and clinicians together in partnership to find cures and treatments for this disease.

Patient voices are essential to gaining a better understanding of this disease and are the drivers who make it possible to accomplish research. We are proud to have initiated two significant patient-led research projects: the patient registry and the biobank.

EHE GLOBAL PATIENT REGISTRY

The EHE Global Patient Registry collects information from people diagnosed with EHE globally. This project will develop a large, long-term database and resource to advance research.

EHE BIOBANK

The EHE Biobank was established to create a centralized biorepository of EHE biospecimens and make them available for research. Working collaboratively, the Biobank aims to significantly advance the development of much needed EHE disease models to accelerate therapeutic development.

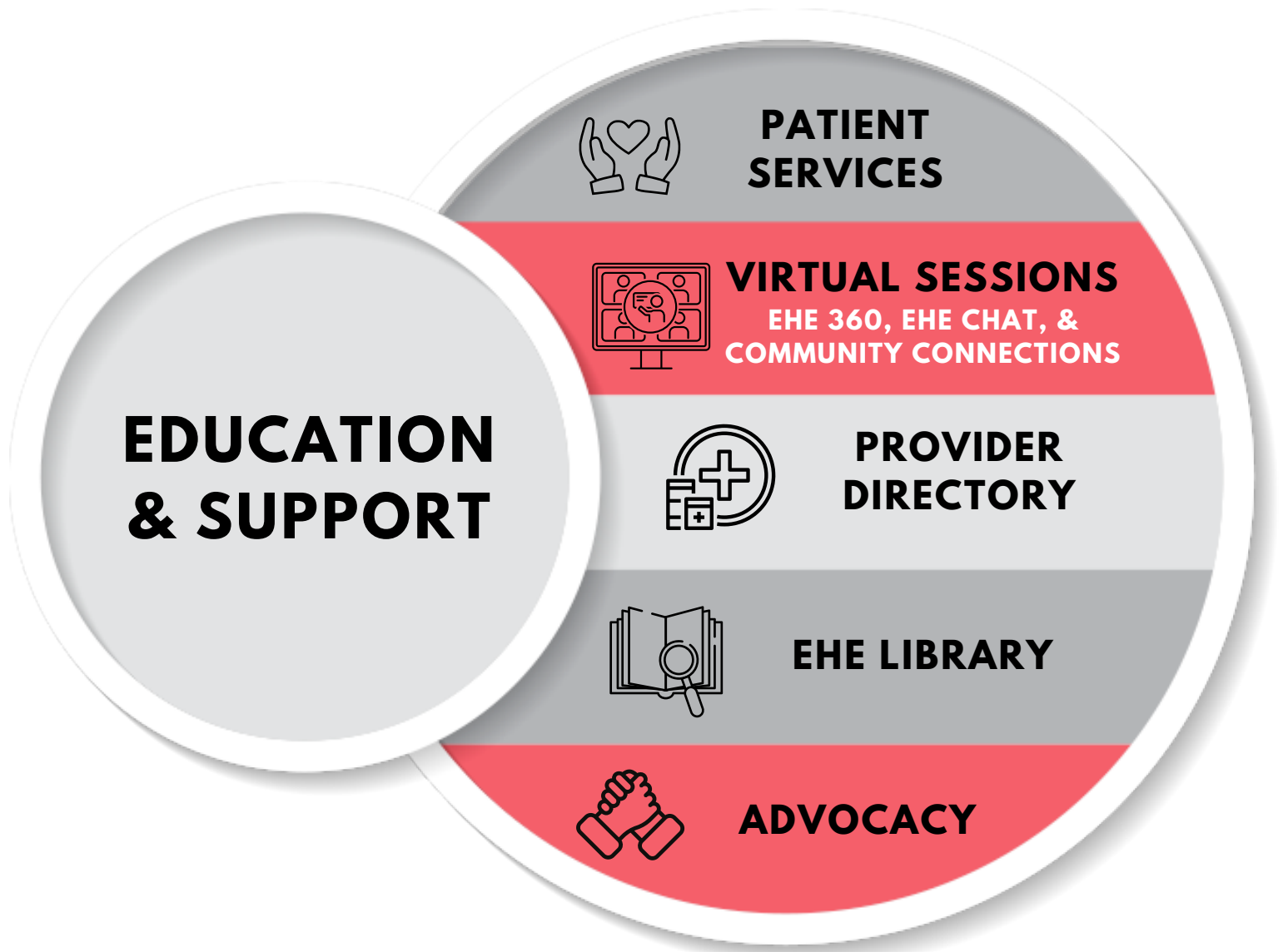


WE ARE PROUD OF OUR PROGRESS

Less than 10 years ago, we had only one research lab focused on EHE and today there are more than 10 world-renowned academic medical centers that have initiated meaningful EHE research projects.

EDUCATION & SUPPORT

We strive to empower patients to advocate for their care through various types of continuing education and support.



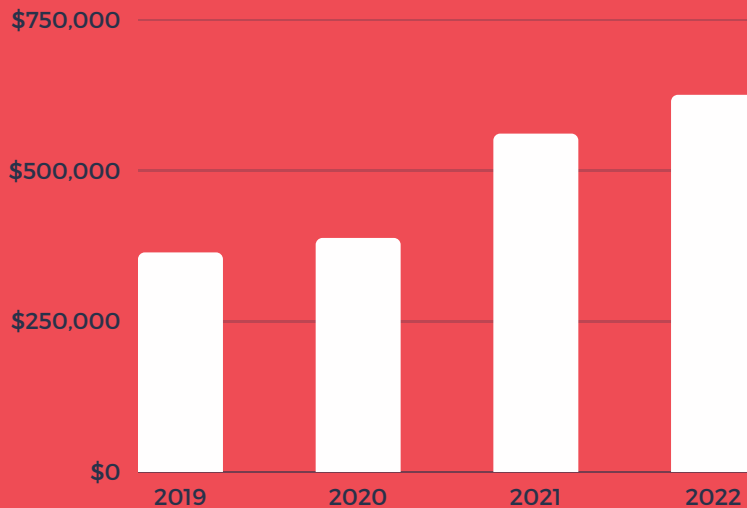
We are grateful to be able to provide education and support. Purposeful outreach and programming aims to:

- Improve clinician awareness of EHE
- Drive better patient outcomes
- Facilitate and encourage research participation
- Spotlight patients' experience and perspectives
- Raise awareness about inequities and disparities
- Identify opportunities to improve care access
- Educate and empower patients as advocates

"The EHE Foundation has helped me advocate for my child's care and given us hope for his future."
-Jen, Parent

OUR INVESTMENTS

The EHE Foundation invests funds strategically in research and educational programming to expand areas of scientific knowledge, perpetuate shared learning across clinical practices, and ensure that patients grow stronger as advocates and partners in finding a cure for their disease.



RESEARCH GRANTS & PROGRAMMING INVESTMENTS

With expert review and guidance, we have strategically invested in high-impact research projects and grants, funding over \$1.5 million in research.

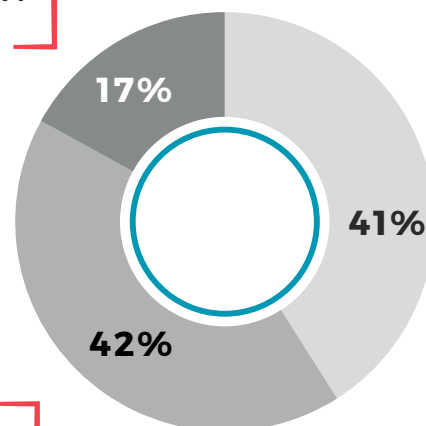
2022 PROGRAMMING INVESTMENTS

To meet our mission, we must sustain investments in education and support and scientific discovery through grants and patient-led research. Each are critical to bring patient voices and experiences forward as key components of success.

PATIENT EDUCATION & SUPPORT

COLLABORATIVE PATIENT-LED RESEARCH

RESEARCH GRANTS PROGRAM



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OUR COMMITMENT TO DIVERSITY, EQUITY, & INCLUSION

We believe that to serve the EHE community to the best of our ability we must make a conscious effort to incorporate diversity, equity, and inclusion in all that we do. As we continue to evolve and grow as an organization, we are committed to building a community that fosters diversity and inclusion, while actively addressing inequities. We will seek to continuously improve to meet the challenges presented to our community to reflect our commitment.

The EHE Foundation will work consciously to incorporate diversity, equity and inclusion in all that we do. To achieve this commitment, we will:

- Build teams, including boards, staff, and volunteers that represent a broad range of ideas and voices, and that represent diversity in our affected patient population.
- Develop programs and resources in which a diverse range of patients, caregivers, clinicians, researchers, and other stakeholders can thrive and grow.
- Foster a community that recognizes, welcomes, and values differences.
- Support research and programming initiatives that have equitable outcomes for all patients.
- Work tirelessly to ensure that all patients and caregivers are provided equal access to the same level of support and care options.

YOUR SUPPORT IS CRITICAL TO OUR MISSION

Your support is transformative for people living with EHE. It will enable us to continue our efforts to meaningfully support patients living with EHE, advance research, and continue essential collaborations between patients, researchers, and clinicians; each necessary to find effective treatments and a cure for this disease. Together, we will continue to make profound progress and make a significant impact in the lives of those affected by EHE.



“

The EHE Foundation has given me amazing support as a patient, education directly from experts, and valuable resources. Even more, they have given me hope for a future without EHE by funding and collaborating promising research.

-Delaney, Patient

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The EHE Foundation

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The EHE Foundation is a registered 501(c)(3) non-profit organization. Tax ID: 47-3238441. Donations to the EHE Foundation are tax deductible to the extent permitted by law. The EHE Foundation is committed to accountability and transparency. Candid, formerly GuideStar, recognizes the organization with its highest rating. Audited financial reports and IRS form 990 tax returns are available upon request.