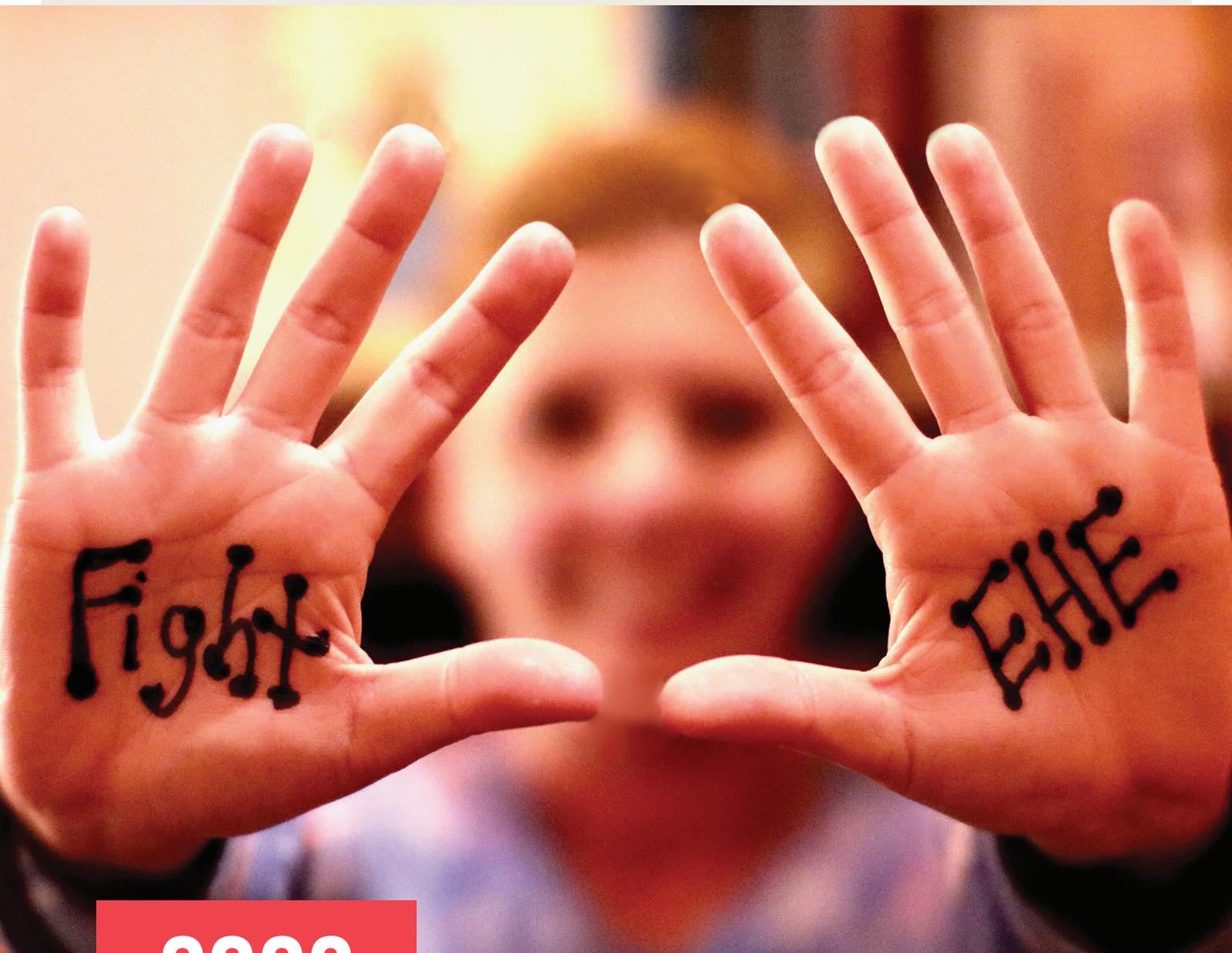


IMPACT REPORT



2023

The leading global advocacy and research organization for epithelioid hemangioendothelioma (EHE)

THE
EHE
FOUNDATION

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Cover Photo: Katherine Czyzewski, EHE patient

Epithelioid Hemangioendothelioma (EHE)

An ultra-rare vascular sarcoma, EHE has no approved systemic treatments or cure, but promising research advances are underway.



LEADING THE CHARGE



Jenni Kovach

President, Board of Directors

The EHE Foundation was gaining momentum long before I encountered the term 'epithelioid hemangioendothelioma' (EHE). When I was diagnosed in 2017, I was relieved to find a nonprofit organization dedicated to this ultra-rare cancer. Run entirely by patient and caregiver volunteers, the Foundation's early years were driven by the urgent need to support a patient population with a largely unknown disease. Upon joining the Foundation, I quickly recognized its crucial role in supporting patients, fostering collaboration among researchers, and providing funding to advance scientific studies.

This past year has been challenging. Our community sadly lost patients, saw many people experience progression of their EHE after years of stability, and watched people endure extensive pain. For me, each of these stories underscores the urgency that I feel. It is a sense of urgency that outpaces the current speed of treatment development.

In response, we have launched important Foundation-led research initiatives: the EHE Biobank and the EHE Global Patient Registry. These projects provide crucial data to advance research. Powered by an engaged community of EHE patients, these initiatives exemplify the proactive steps the Foundation is taking to push research forward.

As our patient community continues to grow with new people diagnosed with EHE, the Foundation's vision of a world where EHE is easily diagnosed and treatable becomes more critical. I am proud to have the opportunity to serve the EHE community in my role at the Foundation. We have come far since the earlier days.

The EHE Foundation 2023 Impact Report instills significant optimism for the future of EHE patients. It reflects the Foundation's progress in bringing our mission to life: to find treatments and a cure for EHE.

Thank you for your support that brings hope to patients like me.

Jenni Kovach



Denise Robinson

Interim Executive Director
& Director of Research

I am excited to present *The EHE Foundation 2023 Impact Report* to the global EHE community. Our work in 2023 was driven by our mission to find treatments and a cure for epithelioid hemangioendothelioma (EHE), striving to support all individuals diagnosed with EHE, regardless of their location.

The year 2023 brought significant challenges and important growth to the Foundation. Growth, while challenging, has deepened our gratitude for the countless hours volunteers have dedicated to unite EHE patients and families. Today, the Foundation stands as a sustainable and enduring entity, committed to the rigorous work of raising funds, investing in groundbreaking research, and pursuing our mission to serve and support people living with EHE and those who will be diagnosed in the future.

The field of rare cancer research is extraordinarily complex. Unlike common diseases and cancers, governments, regulators, and major drug developers make only modest efforts to advance science for ultra-rare populations. Rare and ultra-rare cancers, like EHE, require increased efforts. These challenges impact patients' lives and present significant barriers to translating innovative science from hypothesis into practice. With your support, we are engaging the best minds in science to focus on EHE, accelerating the journey from discovery to treatment.

Our mission is not just a goal; it is the focus of our daily work. We are dedicated to a future where people no longer suffer extensive misdiagnoses and doctors can effectively treat EHE, enabling all people with EHE to live long, fulfilling lives without fear of recurrence or progression.

I invite you to explore our progress – a true testament to the impact of your support. I give my sincerest gratitude to our staff, the Board of Directors, Scientific and Medical Advisors, supporters, and collaborators who have made this critical work possible. Your continued support is deeply appreciated.

Sincerely,

Denise Robinson

CHAMPIONS OF HOPE

The EHE Foundation

As the leading patient advocacy and research organization for epithelioid hemangioendothelioma (EHE), cultivating hope for the thousands of people affected by this ultra-rare disease drives everything we do.



Receiving a cancer diagnosis is devastating for anyone. People diagnosed with EHE suffer the additional burden and stress of realizing **there are no treatments proven to be effective or approved specifically to treat EHE.**

Our mission to “find a cure for EHE by advancing research and driving collaboration among patients, researchers, and clinicians” is not just a phrase we say. We live it, every day. We believe it is reasonable to expect and envision a world where EHE is easily diagnosed and treatable.

Every stakeholder plays a critical role in advancing research. Only by joining together as a collaborative community can we uncover the mysteries of this disease and bring hope to every patient and family affected.



MISSION

Our mission is to find treatments and a cure for the rare cancer, epithelioid hemangioendothelioma (EHE), by advancing research and driving collaboration among patients, researchers, and clinicians.

VISION

We envision a world where EHE is easily diagnosed and treatable.

CULTURE

To meet the needs of those affected by EHE, we are facilitating a culture of collaboration. Each stakeholder holds a critical piece of the puzzle to unlock the mysteries of EHE and bring hope to our community.

ON THE EDGE OF BREAKTHROUGH

EHE Research



The Lamar Lab Research Team

We Are Strong. We Are Tireless. We Work For You.

The EHE Foundation has evolved in recent years from being a volunteer-led organization to a sustainable entity that professionally engages clinician-scientists, researchers, regulatory bodies, and drug developers.

We are bringing the best minds in research and industry to EHE, accelerating the pathway from discovery to treatment, and including the patient's voice at every step.

Our pledge to the EHE community is an unwavering commitment to pioneering research, innovative funding, and groundbreaking drug development for EHE.

Momentum is happening in EHE research and therapeutic development. The EHE Foundation is leading the charge toward a world where EHE is easily diagnosed and treated – better yet, cured!

PROJECTS, INITIATIVES, AND PRIORITIES

EHE GLOBAL PATIENT REGISTRY

EHE BIOBANK

EHE RESEARCH GRANTS PROGRAM

CLINICAL TRIALS

PUBLISHED RESEARCH

GLOBAL COLLABORATION

STRATEGIC PARTNERSHIPS

GLOBAL ADVOCACY



MAKE AN IMPACT

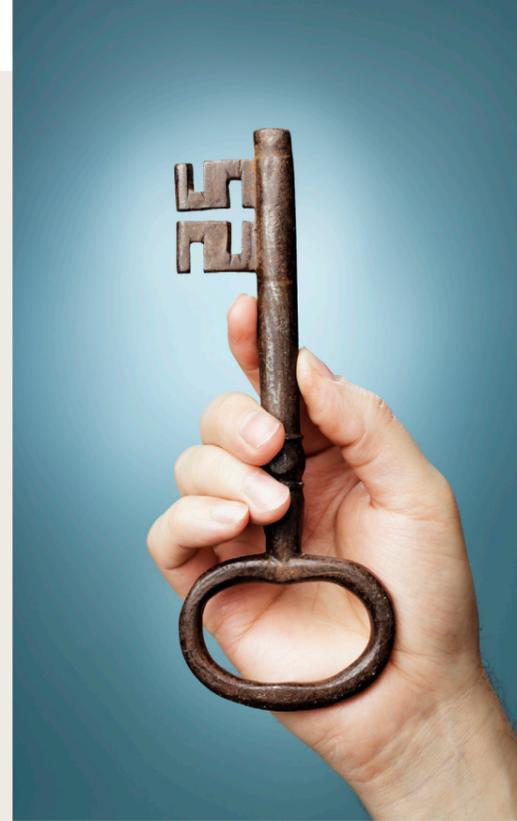
Your gift to EHE research changes lives.

PATIENTS ARE THE KEY TO THE CURE

Patient-Powered Research

When speaking to EHE patients about research, we like to say, "We are doing this work for you, but we cannot do it without you."

Patients are the key to unlocking this disease. Patients are the key to unlocking this disease by contributing their stories, clinical records, and tissue samples to help researchers broaden their understanding of EHE and conduct the critical research necessary to find treatments and a cure.



EHE Global Patient Registry
EHRegistry.iamrare.org

EHE GLOBAL PATIENT REGISTRY

The EHE Global Patient Registry launched in May 2023 as the first ethically approved Natural History Study of EHE, enabling people diagnosed with EHE to power research for a cure. This study provides a simple way to document their EHE diagnosis, symptoms, disease presentation, treatments, and treatment outcomes.

At the end of 2023, more than 200 patients enrolled to share their experiences with EHE.

This landmark research creates an international resource that will reveal disease patterns and generate hypotheses for clinicians and scientists for years to come. Its value becomes increasingly important for identifying clinical

trial participants, thereby accelerating the identification and enrollment processes—historically, a significant challenge for studies involving small populations.



EHE BIOBANK



Patty Cogswell

Patty Cogswell, The EHE Foundation's Biobank Coordinator encourages patients, "You didn't choose to have cancer, but you can make a difference in how the world fights it."

The EHE Biobank is an ethically approved, centralized biorepository and protocol for collecting and storing EHE specimens, including tumor tissue, serosal fluids, and blood, from patients in the United States.

These specimens are crucial for creating human EHE disease models, which help us understand disease biology and progression. Importantly, they are also used in drug screening to identify potential treatments before testing in humans.

Launched in the fall of 2020, the Biobank had 41 specimens from 62 EHE patients by the end of 2023.

Before a procedure, patients consent via DocuSign, and the Biobank Coordinator collaborates with their care teams to prepare for specimen collection, ensuring viability for research. Specimens are sent to the Cleveland Clinic Central Biorepository (CCCB) for quality

assessment and pathology review to confirm an EHE diagnosis. We are grateful for the CCCB team and Dr. Brian Rubin for their efforts in these important processes.

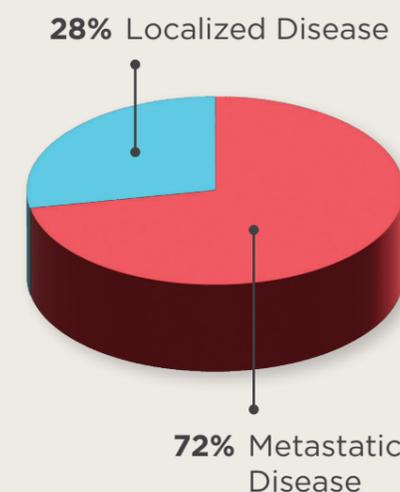
Through approved material transfer agreements, the EHE Biobank has released 5 specimens to develop EHE models as of 2023. We look forward to sharing future results.

Why is EHE biobanking undertaken by advocates?

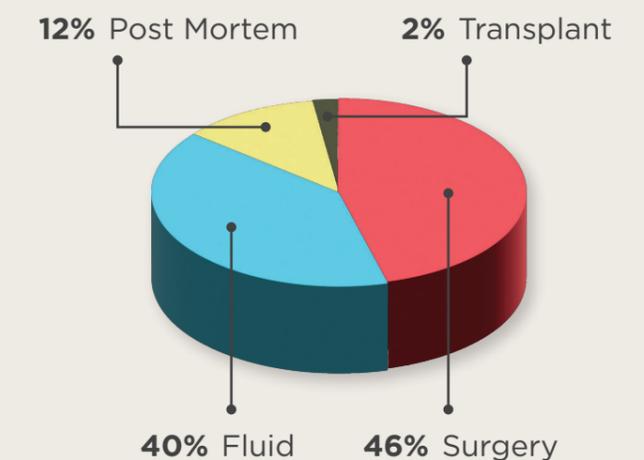
Access to fresh tissue and viable EHE cells is a significant barrier to advancing research. Most often, laboratories where EHE is being studied are not in the same institution where EHE tumors or fluids are removed from patients. This challenge becomes more complex when institutions are reluctant or excessively slow to share tissue. The EHE Biobank overcomes this challenge by facilitating patient-driven tissue requests at the patient's hospital - a request most institutions are willing to accommodate.

Patients and advocates at The EHE Foundation are advancing research through this meaningful project. We are grateful for the generous donations of tissue to advance EHE science and to find treatments for this disease.

Participants' Disease Status



Donations by Procedure Type



ACCELERATING THE CURE

2023 Research Grants Program

Our mission is clear: to discover treatments and, ultimately, a cure for EHE. Along this journey, we must understand the biology of EHE, uncover why it affects individuals differently, and determine what triggers its aggression. Investigating treatment options for the various presentations of the disease is crucial. Answering these and countless other questions is part of our commitment, which includes seeking out expert researchers globally and encouraging their focus on EHE.

Established in 2021, The EHE Foundation's Research Grants Program is dedicated to identifying and funding the most promising basic, translational, and clinical research. Our goal is to advance scientific knowledge of EHE and accelerate the development of effective treatments for patients. Grants are awarded annually, contingent on available funding and alignment with our mission.

RESEARCH GRANTS FUNDED IN 2023

TAZ-CAMTA1 Regulation by the Calcium Sensor Calmodulin

Principal Investigator: John Lamar, PhD, Albany Medical College

Award Amount: \$40,000 Funding in 2023 (Year 3/3 - \$150,000 award for 3 years.)

This project is co-funded in partnership with the EHE Rare Cancer Foundation Australia.

Summary: This project investigates if the protein Calmodulin (CaM) can repress the oncogenic activity of the TAZ-CAMTA1 fusion protein that plays a causal role in more than 90% of all EHE. The research hypothesizes that CaM binds to TAZ-CAMTA1 and blocks its importation into the nucleus where it would normally bind to TEADs and promote the expression of other genes that are necessary for the survival and growth of EHE cells. Based on learnings, the researchers predict that if they can increase CaM expression in EHE cells or treat EHE cells with a peptide that "mimics" CaM, it will reduce the amount of TAZ-CAMTA1 in the nucleus and inhibit its function.

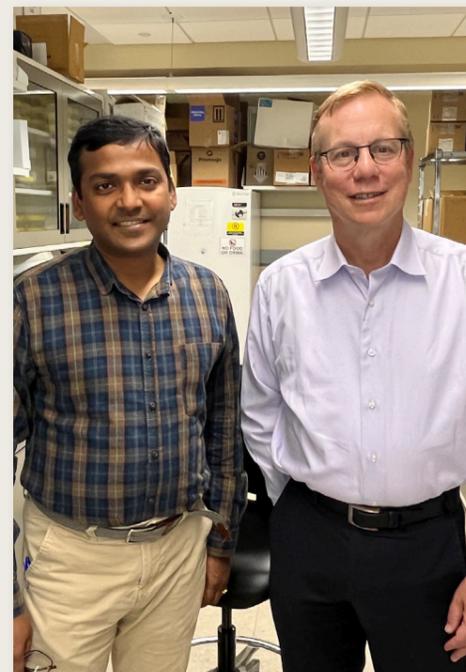
Use of Pre-clinical EHE Models to Identify Druggable Pathways to Treat EHE

Principal Investigator: John Lamar, PhD, Albany Medical College

Award Amount: \$75,000 Funding in 2023 (Year 2/3 - \$450,000 award for 3 years.)

This project is funded cooperatively by a generous private donation restricted to this grant.

Summary: The goal of this project is to identify pathways that can be targeted with existing FDA approved drugs to either eliminate EHE or prevent its growth, providing the rationale to test if these drugs can be repurposed for use in EHE patients. Researchers will use an RNAi screen to identify druggable proteins essential for TAZ-CAMTA1 function in EHE cells, then use pre-clinical EHE mouse model systems to test existing drugs that target the identified proteins as potential treatments for EHE. EHE cell lines generated from a genetically engineered mouse model of EHE will be exploited for both the in vitro RNAi screen and to generate EHE-bearing mice to test potential therapies.



Ajaybabu Pobbati, PhD & Brian Rubin, MD, PhD

Harnessing FDA-Approved Drugs to Gain Mechanistic Insight into the Regulation of the TAZ-CAMTA1 Fusion Protein

Principal Investigators: Ajaybabu Pobbati, PhD and Brian Rubin, MD, PhD, Cleveland Clinic Foundation

Award Amount: \$30,000

Summary: This project builds upon data generated from the grant awarded to Dr. Pobbati in 2022, entitled *Repurposing an FDA-approved Drug for EHE Treatment*. This expanded project aims to further investigate pilot study data from the prior grant that identified drugs that regulate the location of TAZ(WWTR1)-CAMTA1 (TC) fusion gene within the nucleus of the cell and cause it to become unstable, ultimately causing TC to degrade and disappear. Experiments in this study will help better understand this phenomenon, and further investigate the drug(s) uncovered in the pilot study. The drugs of study are FDA-approved and shown to have a good safety profile. Ultimately, this research aims to evaluate if any of the identified drugs can be used to treat aggressive EHE.

Creation and Characterization of an EHE Extended Primary Cell Culture

Principal Investigator: Munir Tanas, MD, University of Iowa

Award Amount: \$36,800

Summary: A significant limitation in the field is the lack of human EHE cell lines or extended primary cell culture, leading to a gap in knowledge. This research aims to create EHE cell lines or extended primary cell cultures. Further objectives are to characterize created primary cells and determine the role of the TAZ-CAMTA1 fusion protein (or YAP-TFE3 protein) for various hallmarks of cancer in EHE cells. Importantly, this research leverages the EHE Biobank, an ethically approved central repository of EHE tissue and fluids donated by consented participants and released as de-identified specimens for research.

Evaluation of Cytokines and Hormones as Biomarkers for EHE

Principal Investigators: Silvia Stacchiotti, MD and Nadia Zaffaroni, PhD, Istituto Nazionale dei Tumori (INT) Milan, Paul Huang, PhD, The Institute of Cancer Research, London, UK, Professor Robin Jones, Royal Marsden Hospital, London, UK

Award Amount: \$73,992 (Funding Year 3/3)

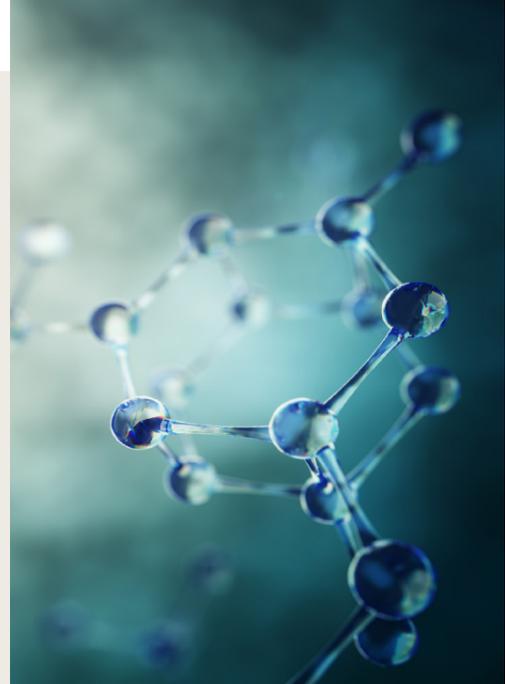
This project is co-funded in partnership with The EHE Rare Cancer Charity (UK).

Summary: This multi-center international collaborative project comprises a number of key objectives including identifying and validating novel biomarkers (prognostic and predictive markers) of EHE to inform patient management and identify potential therapeutic targets; to develop patient-derived xenograft (PDX) models using tumor specimens obtained from study participants; to create PDX-derived cell lines - these preclinical models will be used to comparatively assess the activity of drugs to treat EHE; to describe the natural history of the disease and its radiologic features; and to collect prospective data on quality of life and the activity of systemic agents administered in EHE.

GLOBAL MOMENTUM

Advancing EHE Science

With awareness of EHE spreading globally, research advancements and pharmaceutical interests are growing. There is true momentum in the field of EHE science, research, and clinical trials, and The EHE Foundation is fostering collaboration and participation toward our common goal of improving the lives of EHE patients everywhere.



PUBLISHED RESEARCH



The EHE Library at FightEHE.org continues to grow as researchers, clinician-scientists, and advocates generate a growing complement of publications demonstrating significant scientific advances and creating a much-needed knowledge base about the disease. According to PubMed®, a searchable database developed and maintained by the National Center for Biotechnology Information and the National Library of Medicine, there are 91 publications attributed to epithelioid hemangioendothelioma in 2023.

Below are some of the key publications and shared knowledge from 2023:

Current Model Systems for Investigating Epithelioid Haemangioendothelioma. *Cancers (Basel)*. 2023 May. Neil E., Kouskoff V. <https://doi.org/10.3390/cancers15113005>.

Prognostic Factors in Epithelioid Hemangioendothelioma: Analysis of a Nationwide Molecularly/Immunohistochemically Confirmed Cohort of 57 Cases. *Cancers (Basel)*. 2023 June. Tomassen T., Versleijen-Jonkers Y.M.H., Hillebrandt-Roeffen M.H.S., Van Cleef P.H.J., van Dalen T., Weidema M.E., Desar I.M.E., Flucke U., van Gorp J.M. <https://doi.org/10.3390/cancers15133304>.

Incidence, demographics, and survival of malignant hemangioendothelioma in the United States. *Cancer Med*. 2023 Jul. Paulson K.G., Ravi V., Rubin B.P., Park M., Loggers E.T., Cranmer L.D., Wagner M.J. <https://doi.org/10.1002/cam4.6181>.

Loss of CDKN2A Cooperates with WWTR1(TAZ)-CAMTA1 Gene Fusion to Promote Tumor Progression in Epithelioid Hemangioendothelioma. *Clin Cancer Res*. 2023 July. Seavey C.N., Hallett A., Li S., Che K., Pobbati A.V., Ma S., Burtscher A., Kanai R., Lamar J.M., Rubin B.P. <https://doi.org/10.1158/1078-0432.CCR-22-2497>.

Epithelioid hemangio-endothelioma (EHE) in NETSARC: The nationwide series of 267 patients over 12 years. *Eur J Cancer*. 2023 Oct. Blay J.Y., et. al., NETSARC/REPPS/RESOS and French Sarcoma Group-Groupe d'Etude des Tumeurs Osseuses (GSF-GETO) networks. <https://doi.org/10.1016/j.ejca.2023.113262>.

The oncogenic fusion protein TAZ::CAMTA1 promotes genomic instability and senescence through hypertranscription. *Commun Biol* 6, 1174. 2023. Neil E., Paredes R., Pooley O., et al. <https://doi.org/10.1038/s42003-023-05540-4>.

CLINICAL TRIALS FOR EHE

Currently, no systemic therapies are approved to treat EHE, and only four prospective clinical trials specifically investigating agents to treat EHE, have been completed. Clinical trials offer opportunities for hope to patients and families. They are the bridge - the only pathway to develop new treatments for any disease. We are indebted to patients who have volunteered to advance research with their participation in these studies and to the investigators and researchers who have brought forward these opportunities.

TEAD Inhibitors for EHE

In 2023, the ongoing enrollment of two first-in-human novel TEAD inhibitor studies was a beacon of hope for the future of treating EHE and other solid tumors. TEAD inhibitors are small molecules that inhibit the auto-palmitoylation of the transcription factor TEAD (TEA domain). By inhibiting TEAD auto-palmitoylation, TEAD inhibitors can disrupt the interaction between TEAD and the transcription co-activators yes-associated protein 1 (YAP) and transcriptional co-activator with PDZ-binding motif (TAZ). This disruption may inhibit YAP/TAZ-TEAD-promoted gene transcription, which is involved in tumor cell proliferation and survival.

IAG933 - Novartis Pharmaceuticals

NCT04857372

A Phase I Study of IAG933 in Patients With Advanced Mesothelioma and Other Solid Tumors

IK-930 - Ikena Oncology

NCT05228015

Oral TEAD Inhibitor Targeting the Hippo Pathway in Subjects With Advanced Solid Tumors

Other Studies

The Epithelioid Hemangioendothelioma Registry of the European Reference Network on Rare Adult Solid Cancers (EURACAN) (EHE)

In the context of EURACAN, a hospital-based registry was established in 21 sarcoma reference centers across Europe, including adult patients with a molecularly confirmed diagnosis of EHE. The registry aims to improve the understanding of the natural history of EHE, validate and improve prognostic and predictive factors, and

clarify the activity and efficacy of currently available treatment options, and describe treatment patterns.



Natural History Study of Rare Solid Tumors

Taking place at the NIH Clinical Center in Bethesda, Maryland, this longitudinal and observational study which is open to EHE patients, collects information and samples from people with rare tumors and their relatives, and tracks their health history over a long period of

time. The goal is to learn more about how rare tumors develop and progress and find new ways to control them.



ELEVATING PATIENTS' VOICES

Global Advocacy and Awareness

There is global momentum in EHE awareness. As part of our mission to advance research and drive collaboration, we strategically partner with multidisciplinary stakeholders and allied EHE advocates worldwide to enhance the lives of EHE patients everywhere.

PATIENT ADVOCACY FOR DRUG REPURPOSING



In February 2023, a global survey was developed in partnership with the EHE Rare Cancer Charity (UK) to gather patients' perspectives and experiences on sirolimus for EHE treatment. This impactful survey arose from an initiative of advocates to seek label approval of sirolimus (Rapamune®) for the treatment of EHE from the European Medicines Agency (EMA). This survey aimed to gather patient-donated data to supplement published study data as part of a submission package to the Agency.

In the survey, 130 patients and caregivers

from 21 countries shared their perspectives and experiences regarding the use and accessibility of sirolimus for EHE. Results showed positive results of the drug, including maintaining disease stability and/or tumor shrinkage. Additionally, the longevity of treatment with sirolimus was an important result. Importantly, the survey also reported negative results and experiences, demonstrating that the drug may work well for some patients and not for others.

This survey amplifies the limitations and barriers to care some EHE patients face, where 76% of respondents indicate that it is "hugely important" to have sirolimus available for the treatment of EHE. The survey results were ultimately analyzed for publication in late 2023.

EHE ON PODCASTS



Jane Gutkovich
The Patient From Hell Podcast
February

Denise Robinson
SARC Talk
March



EHE GROUP

The EHE Group is an alliance of EHE advocacy organizations including Australia, Canada, Italy, United Kingdom, and United States. These organizations also provide supportive resources to EHE patients and families and advance research in their regions.



EHE Canada



PARTNERSHIPS & COLLABORATIONS



BOOTS ON THE GROUND

Attendance and participation in international scientific meetings and conferences is essential to the advancement of research and advocacy.

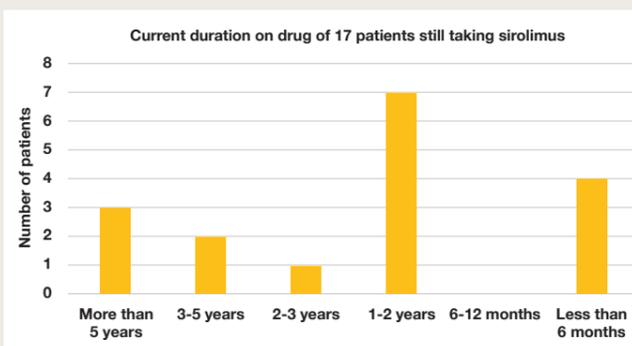
CZI Rare As One Network 2023 Community Meeting
Virtual; January

ASCO 2023 Annual Meeting
American Society of Clinical Oncology
Chicago, IL, USA; June

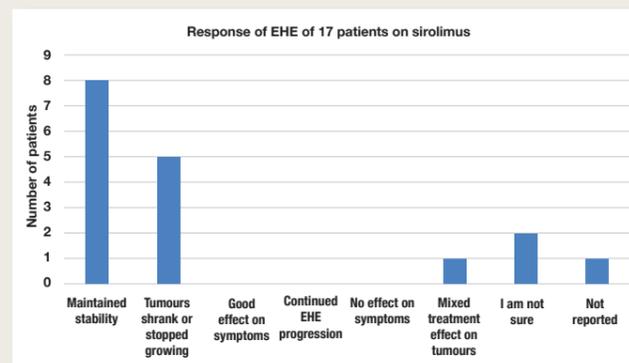
SARC Semi-Annual Meeting
Sarcoma Alliance for Research Through Collaboration
Chicago, IL, USA; June

EHE Global Research Collaboration
Milan, Italy; September

CTOS 2023 Annual Meeting
Connective Tissue Oncology Society
Dublin, Ireland; November



Pre-publication data: longevity of treatment is encouraging, illustrating positive response and tolerability.



Pre-publication data: patients overwhelmingly indicated positive response and disease control.

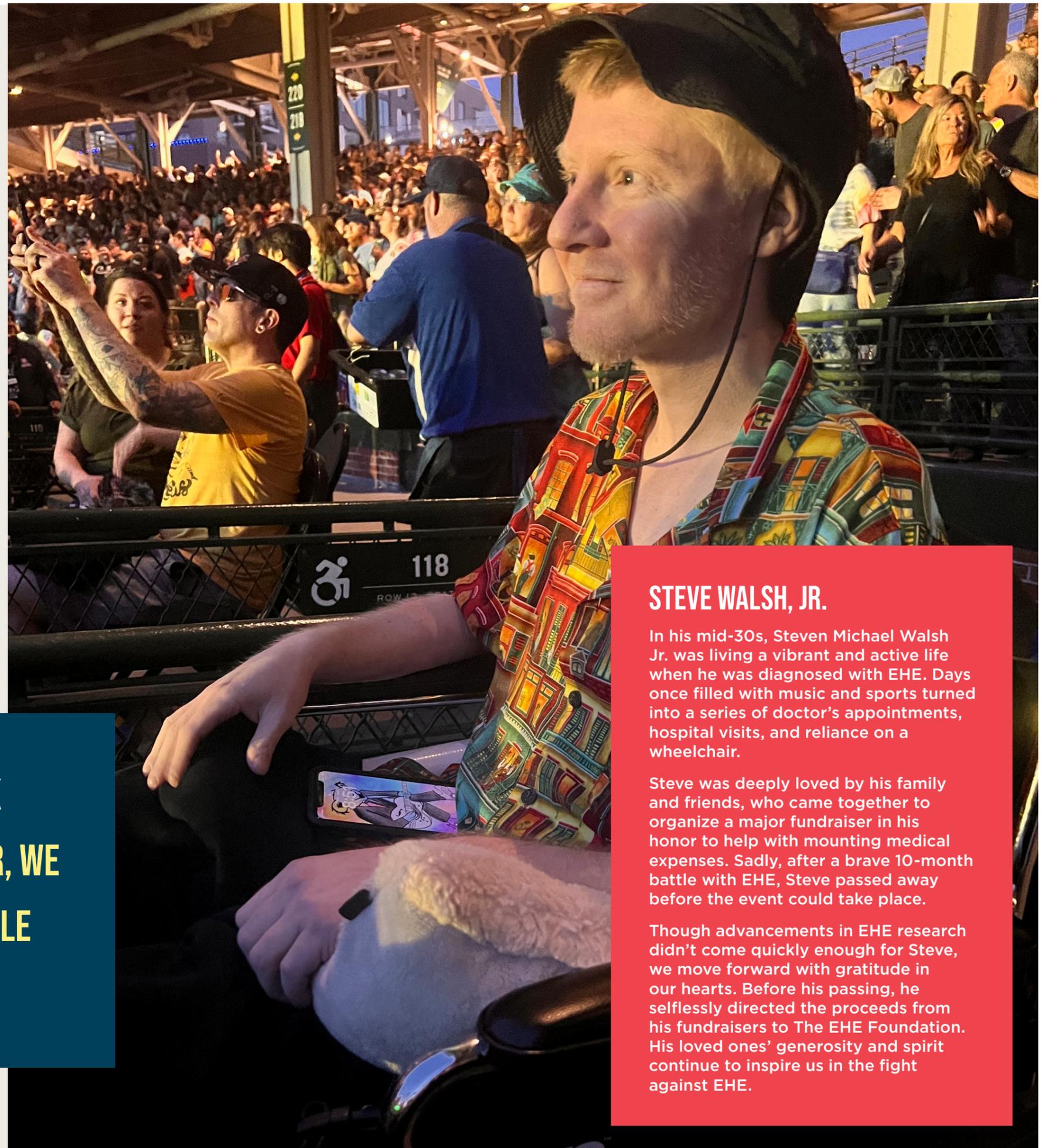
THE FIGHT IS REAL FOR THOSE DIAGNOSED WITH EHE

People living with EHE are at the heart of what we do.

Less than one in one million people are estimated to have EHE. This means that most doctors will never treat a patient with EHE in their career, challenging the notion of receiving “experienced” care from local hospitals and medical centers.

EHE is a highly unpredictable disease, capable of manifesting anywhere in the body and presenting in forms ranging from indolent to very aggressive, often accompanied by devastating pain. There are currently no proven effective treatments or consistent clinical guidelines on when and how to treat EHE. Consequently, patients endure the anxiety of active surveillance (“watch-and-wait”) and are saddled with difficult decisions regarding their treatment options.

**WITH CONTINUED MISSION-DRIVEN WORK
BACKED BY OUR SUPPORTERS, TOGETHER, WE
WILL TRANSFORM THE FUTURE FOR PEOPLE
LIVING WITH EHE.**



STEVE WALSH, JR.

In his mid-30s, Steven Michael Walsh Jr. was living a vibrant and active life when he was diagnosed with EHE. Days once filled with music and sports turned into a series of doctor’s appointments, hospital visits, and reliance on a wheelchair.

Steve was deeply loved by his family and friends, who came together to organize a major fundraiser in his honor to help with mounting medical expenses. Sadly, after a brave 10-month battle with EHE, Steve passed away before the event could take place.

Though advancements in EHE research didn’t come quickly enough for Steve, we move forward with gratitude in our hearts. Before his passing, he selflessly directed the proceeds from his fundraisers to The EHE Foundation. His loved ones’ generosity and spirit continue to inspire us in the fight against EHE.

KNOWLEDGE IS EMPOWERING

Patient Education and Support

Educational programming and resources empower patients to be informed advocates of their EHE journey. We bring all EHE community stakeholders together to learn from each other and move the needle on EHE science to improve clinical care for patients everywhere.

EHE 360 EMPOWERING PATIENTS 2023 GLOBAL PATIENT CONFERENCE



250+
REGISTRANTS



21
COUNTRIES REPRESENTED



1182
NUMBER OF TIMES RECORDINGS HAVE BEEN REPLAYED

Our second annual patient meeting featured an international group of clinicians and scientists presenting the latest clinical and research developments in EHE. Held on April 14, 2023, the conference theme, “Empowerment,” provided an opportunity for attendees to learn and grow in their knowledge of EHE.

More than 180 people attended the live virtual event. A highlight of the convening was the *Ask the Expert* panel, which remains a popular session among patients and clinicians. Anytime we can gather this many people together to talk about EHE - it is amazing! We are grateful to volunteers from the community and the speakers who generously gave their time to make this an impactful event. Recordings are available on our website and YouTube.



“I found the conference to be very worthwhile and professional. I’m extremely grateful to participate and overall heartened that so many talented people are working hard on behalf of those with EHE.”

- Gianna, Conference Attendee

2023 EHE 360 Presentations

Denise Robinson
THE EHE FOUNDATION
Patient-Led Research: Power in Numbers

Brian Rubin, MD, PhD
CLEVELAND CLINIC
EHE 101: What You Need to Know

Breelyn Wilky, MD
UNIVERSITY OF COLORADO CANCER CENTER
Systemic Treatment Options and Triaging EHE

Ajaybabu Pobbati, PhD
CLEVELAND CLINIC
Why TEAD is a Convincing Target for EHE Treatment

Denise Adams, MD
CHILDREN’S HOSPITAL OF PHILADELPHIA
Sirolimus as a Treatment Option for EHE

Hugh Leonard
CHAIR OF TRUSTEES, EHE RARE CANCER CHARITY (UK)
Patients’ Perspectives on Sirolimus

Michael J. Wagner, MD
FRED HUTCH CANCER CENTER
Indolent or Aggressive? EHE Outcomes and Monitoring Strategies

Ask the Expert Panel:

Vinod Ravi, MD
MD ANDERSON CANCER CENTER

Abha Gupta, MD
PRINCESS MARGARET CANCER CENTER

Tamara Vesel, MD
TUFTS UNIVERSITY SCHOOL OF MEDICINE

William Tap, MD
MEMORIAL SLOAN KETTERING CANCER CENTER

EHE COMMUNITY CONNECTIONS

Designed as interactive, educational, and supportive events, EHE Community Connections is in its second year. With both scientific and self-help topics featured, attendance and interest continue to grow.



Science Saturday - Highlights in EHE Research (January)

Cancer Identity - Session 4 (April)

TEAD Talk - The Pursuit of a Treatment and Cure for EHE (June)

David Casimir, PhD, JD, provided a patient-level presentation on the Hippo pathway and TEAD, how they are used to develop EHE treatments, and how these treatments will move from the laboratory, through clinical trials, to patient care. With over 60 attendees, this was one of the most popular EHE Community Connections presentations, demonstrating our community’s thirst for scientific knowledge!

Championing Our Cause: How Patients Support Fundraising (September)



150+
REGISTRANTS



282
NUMBER OF TIMES RECORDINGS HAVE BEEN REPLAYED

EMPOWERMENT ON DEMAND



FightEHE.org

FightEHE.org provides verified and reliable information about EHE to help patients and their caregivers find their footing and navigate their journey from a place of empowerment and knowledge. Often, it is the first place people newly diagnosed with EHE learn about this ultra-rare disease and where veteran community members return for the latest events, EHE research, and supportive resources. FightEHE.org is an important place to spend time and return to frequently because knowledge is power.



Resources for the Newly Diagnosed

Thoughtfully revised during 2023, the Newly Diagnosed section of the website includes salient resources and step-by-step instructions to help those newly diagnosed know where to start.

People newly diagnosed with EHE are overwhelmed. Not only are they learning they have cancer, they're also coming to terms with the rarity of this disease and how that impacts their potential treatment. To help, we've outlined the first steps which include finding an experienced provider and preparing for a first appointment, learning about EHE, and connecting with The EHE Foundation as a trusted, ongoing resource.

PREPARE FOR YOUR
APPOINTMENT
AFTER YOUR EHE DIAGNOSIS

Developed in 2023, the Appointment Checklist provides a comprehensive list of tasks and questions designed to empower patients to advocate for their care—helpful in an ultra-rare disease like EHE, where patients are burdened with an outsized role in determining their care and treatment plan.



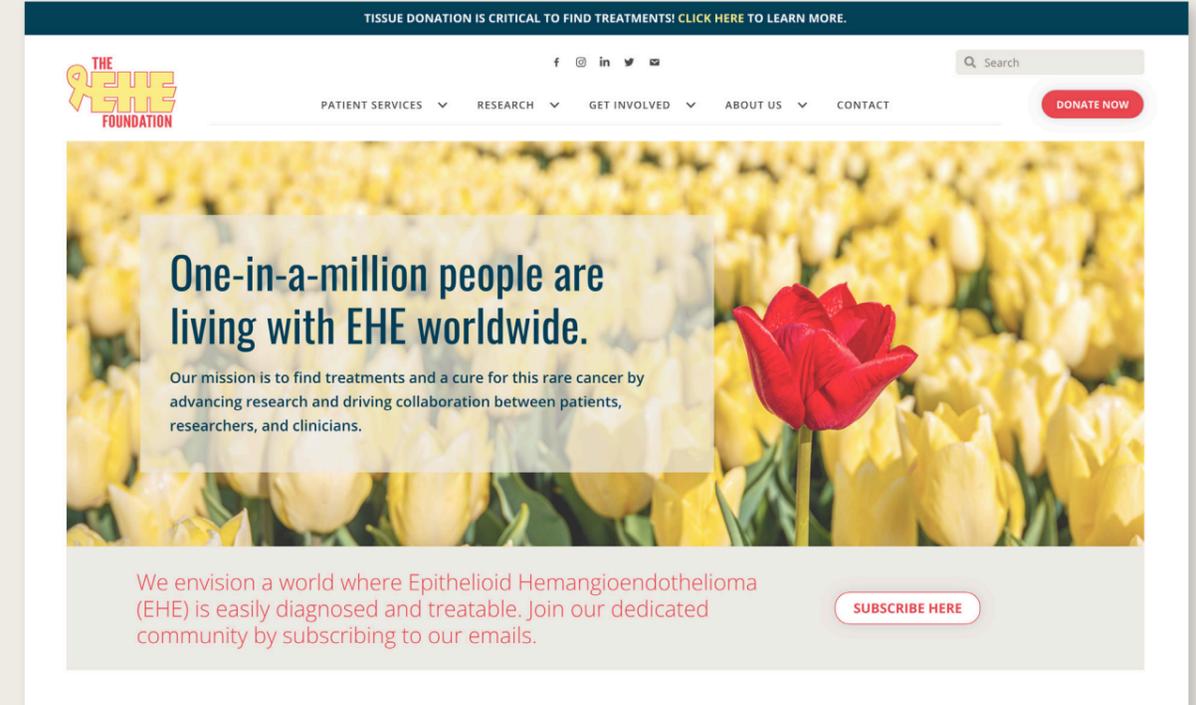
EHE Library

The EHE Library continues to grow as researchers, clinician-scientists, and advocates generate a growing complement of publications demonstrating significant scientific advances and creating a much-needed knowledge base about the disease. With over 200 publications, including case reports, published research, and other articles, this continuously updated, searchable resource is a catalog of progress in EHE science.



Provider Directory

Patients are encouraged to confirm their diagnosis and seek care with a sarcoma expert who is experienced in the management of EHE. Ideally, these specialists practice at large academic medical centers equipped to provide multi-disciplinary treatment approaches for EHE and other rare cancers. This continually curated directory allows patients to quickly identify providers experienced in the variability of EHE.



EHE News

FightEHE.org is where people sign up for The EHE Foundation's newsletter, in which we share the latest information about EHE to a growing subscriber base of over 2300 patients, caregivers, donors, clinicians, researchers, and industry professionals. Featuring EHE research, science, events, and fundraising activities, we deliver accurate and reliable information from a place of experience and knowledge.



Educational Recordings on Demand

EHE 360 Empowering Patients 2023 Global Patient Conference recordings are available on demand at fightehe.org and YouTube. With these added, the EHE Foundation YouTube channel now holds over 65 videos providing hours of streaming content on EHE clinical practice, research advances, Community Connections, and patient videos. These recordings serve as a sustainable resource for the EHE community.



Consensus Paper on EHE Management

Published in 2021, this paper is the first, and only publication of experts' guidance for managing EHE. This key resource is a must-read for everyone diagnosed with EHE and clinicians unfamiliar with the disease.

ALL IN FOR EHE

Every gift makes a difference.

Your generosity and dedication are instrumental to finding a cure for EHE. Your contributions enable us to drive groundbreaking research, provide essential educational resources to patients and clinicians, and raise awareness about epithelioid hemangioendothelioma (EHE). Together, we are making significant strides in the fight against this ultra-rare cancer. Your unwavering commitment is our fuel for progress.



COMMUNITY-HOSTED EVENTS

In 2023, two communities rallied to celebrate their loved ones with heart-touching events. We are sincerely grateful for these communities who raised awareness about the critical need to advance EHE research while raising over \$45,000 combined to benefit The EHE Foundation. These significant efforts are complemented by many other events that put the 'fun' in fundraising.



Good Vibes for McKenna (January)

Held in Ft. Myers Florida in memory of McKenna Helm, the 2nd Annual Good Vibes for McKenna live concert drew nationally recognized musicians for a performance and private dinner. In total, the Good Vibes for McKenna nonprofit organization donated more than \$25,000 to benefit The EHE Foundation.



Shakedown for Steve (October)

Held at 115 Bourbon Street, a staple of Chicago's Southside, family and friends honored the memory of Steve Walsh at Shakedown for Steve. Originally planned to help Steve with mounting medical bills, the fundraiser became a celebration of life when Steve passed away in September 2023. In total, \$20,000 was donated to The EHE Foundation in his memory.

GIVING TUESDAY

Harnessing the power of this global day of giving, The EHE Foundation's annual end-of-year campaign centers around Giving Tuesday. With campaign funds dedicated to supporting EHE research, our generous community did not hold back. **For 2023, donations totaled more than \$84,000! With an incredibly generous \$75,000 match by our Board of Directors, the campaign total was \$159,000!**



TRIBUTE GIFTS

Honorary and memorial gifts, also called tribute gifts, contribute to the financial stability and growth of our organization and create a lasting legacy for the honoree or deceased, preserving their memory and honoring their patient journey. **In 2023, we are grateful to have received more than \$112,000 in honor of, and more than \$55,700 in memory of, EHE patients.**

GRANTS

Grant-seeking is the process of identifying, researching, and applying for financial grants provided by government agencies, foundations, corporations, or other organizations. These grants are typically awarded to support specific projects, programs, or initiatives that align with the grantor's mission and goals. With a comparatively small patient population to other cancers and diseases, the competition for grant money is fierce. **In 2023, we were fortunate to have received more than \$55,000 in restricted and unrestricted capacity-building grants.**

CORPORATE GIVING

A growing stream of revenue for The EHE Foundation is corporate giving. Matching gifts, sponsorships, workplace giving, and grants are all powerful ways businesses can make a big impact in our small community. **In 2023, nearly \$5,000 was attributed to corporate giving.**



The Fundraising Toolkit was produced by the Development Committee in 2023. Packed with ideas, tips, and instructions, this downloadable resource supports and inspires community events.

AWARENESS + FUNDRAISING = IMPACT

The 2023 EHE Fun Run & Walk

Our most popular awareness and fundraising event of the year, the virtual 2023 EHE Fun Run & Walk, united our community in support of patients, spreading EHE awareness and raising funds to drive EHE research.

With registration held in April, during EHE Awareness Month, this year's theme was "Shine a Light on Rare Cancer." Community events, big and small, were held across the United States, with our largest team generating over \$16,000 in registrations and donations. Each year, this event brings our community together like no other. In 2023, we raised over \$60,000 with 1,156 registrations and more than 60 teams!

Thank you to EHE patient Kim Young for designing the 2023 event logo!

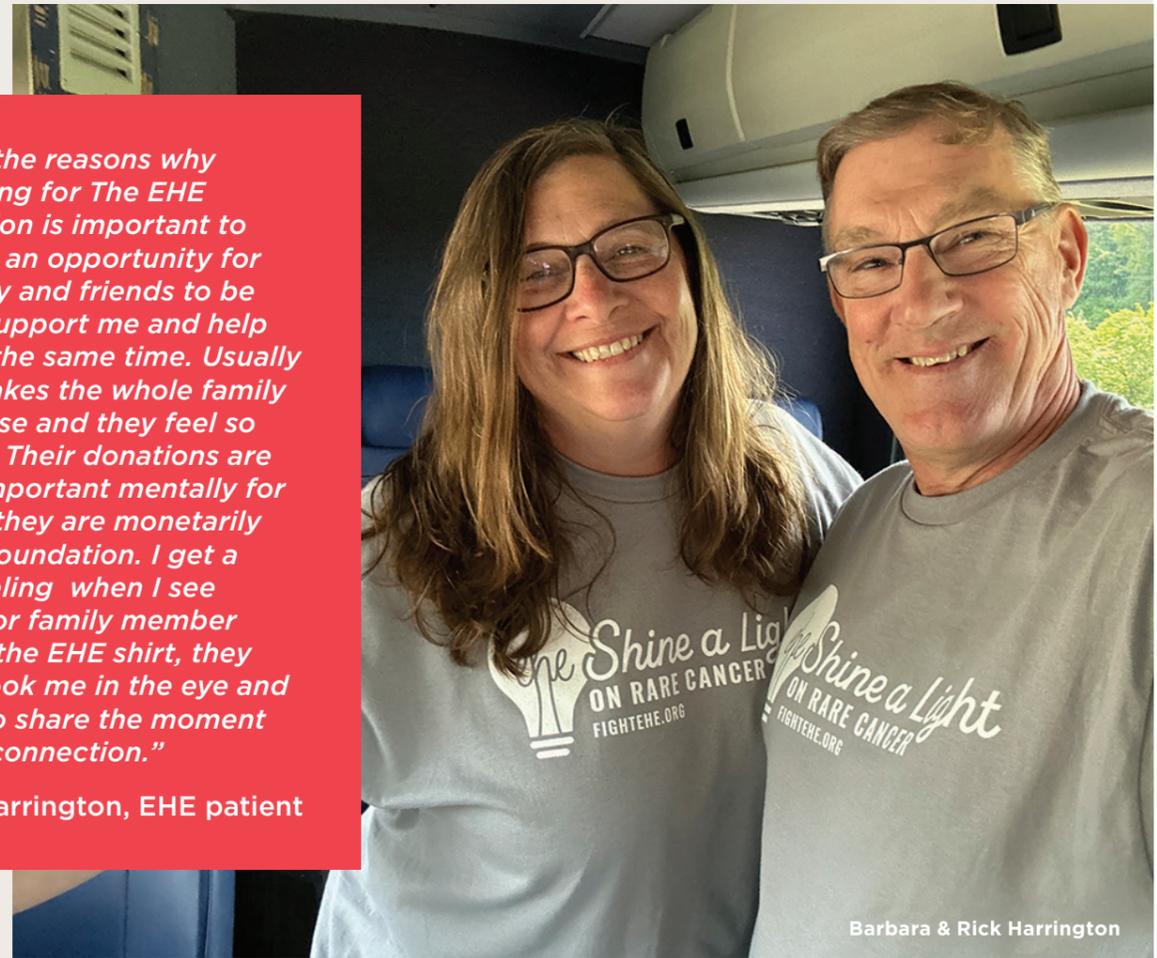

1156
REGISTERED PARTICIPANTS


60+
TEAMS RALLIED FOR EHE PATIENTS


\$60k+
AMOUNT RAISED

"One of the reasons why fundraising for The EHE Foundation is important to me is it's an opportunity for my family and friends to be able to support me and help them at the same time. Usually cancer takes the whole family by surprise and they feel so helpless. Their donations are just as important mentally for them as they are monetarily for the Foundation. I get a great feeling when I see a friend or family member wearing the EHE shirt, they always look me in the eye and we get to share the moment and the connection."

- Rick Harrington, EHE patient



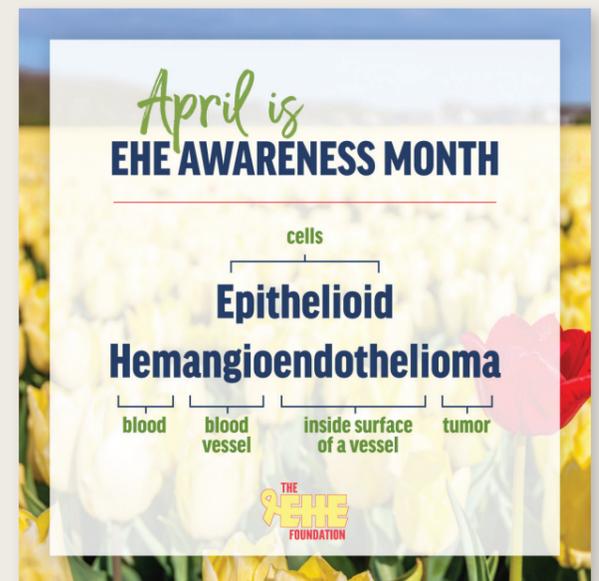
Barbara & Rick Harrington



EHE AWARENESS MONTH

Awareness is a critical pillar of progress for a rare disease. By raising EHE awareness, we ignite research interest, attract funding, and stimulate pharmaceutical activity. Throughout April, in addition to spreading awareness with the 2023 Fun Run & Walk, we shared patient stories, highlighted groundbreaking research, and disseminated crucial EHE facts, resonating deeply within our community and beyond.

This annual global campaign strives to extend EHE awareness beyond our immediate circle. Our goal is to enhance patient support, capture the interest of external funders, and draw significant attention from the scientific community. By spreading knowledge and understanding, we pave the way for advancements that can transform the lives of EHE patients everywhere.



TEAMWORK

The EHE Foundation

The work of a rare-disease patient advocacy and research foundation demands perseverance and significant resources. In commitment to our mission to find treatments and a cure for EHE, we are focused on sustainable growth with a talented and dedicated team of staff, volunteer board members, advisors, and volunteers. Since our founding in 2015, we have remained committed to making a lasting impact in the fight against this rare disease. The EHE Foundation is prepared to guide scientific research from the lab bench to a cure for EHE.

Diversity, Equity, and Inclusivity (DEI)

The EHE Foundation is committed to fostering a diverse, equitable, and inclusive environment for both our team and the community we serve. We pledge to support our diverse population with compassion, representation, and acceptance. Our commitment to DEI is foundational to our mission and integral to all our initiatives, ensuring that every voice is heard and valued.

FOUNDATION TEAM

Denise Robinson

Interim Executive Director
& Director of Research

Maggie Cameron

Director of Development & Communications

Julie Wahl

Finance Manager
& Patient Advocate

Patty Cogswell

EHE Biobank Principal Investigator

VOLUNTEERS

Our dedicated community volunteers are the backbone of our efforts. Their talents enhance our events and projects, while their outreach brings new patients to our resources and opportunities. We are forever grateful for their support and confidence.

BOARD OF DIRECTORS

Jenni Kovach

President

Amy Baghdadi, JD

Secretary

Sarah Bright

Treasurer

David A. Casimir, JD, PhD

LeeAnn Conner

John McFadden, PhD, CRNA, APRN*

Guy Weinberg, MD*

Jane Gutkovich

Cofounder, Board Member Emeritus

Julie Wahl

Cofounder, Board Member Emeritus

**Joined the Board in 2023*

ADVISORY BOARD

Denise Adams, MD

Children's Hospital of Philadelphia

Scott Okuno, MD

Mayo Clinic

Vinod Ravi, MD

MD Anderson Cancer Center

Brian Rubin, MD, PhD

Cleveland Clinic

Silvia Stacchiotti, MD

Fondazione IRCCS Istituto Nazionale
dei Tumori

William Tap, MD

Memorial Sloan Kettering Cancer Center

Cameron Trenor III, MD

Boston Children's Hospital

Jonathan C. Trent, MD, PhD

Sylvester Comprehensive Cancer Center

Breelyn Wilky, MD

University of Colorado Cancer Center



COURTNEY BIEGLER

Diagnosed in 2023, Courtney Bieghler is a young mother who is fighting for a future she dreams of.

"I fight for my family. My husband and my four-year-old daughter. She is too young to understand what cancer is and I need her to know that her mother is going to fight to be here for when she graduates from college, on her wedding day, and the day she becomes a mother herself."

The EHE Foundation fights alongside patients like Courtney, ensuring that their goals and dreams remain within reach. Through research, advocacy, and community support, we provide hope to families facing the challenges of EHE.

FINANCIALS

Statement of Financial Position December 31, 2023

	2023
<u>Assets</u>	
Cash and cash equivalents	\$ 970,974
Contributions receivable	28,579
Grant receivable - multi-year	50,000
Investments	852,868
Investment fund - board designated	-
Total assets	\$ 1,902,421
<u>Liabilities and net assets</u>	
<u>Liabilities</u>	
Accounts payable	\$ 76,830
Grants payable - multi-year	100,000
	176,830
<u>Net assets</u>	
Without donor restrictions	
Undesignated	1,478,491
Board designated	-
	1,478,491
With donor restrictions	247,100
Total net assets	1,725,591
Total liabilities and net assets	\$ 1,902,421

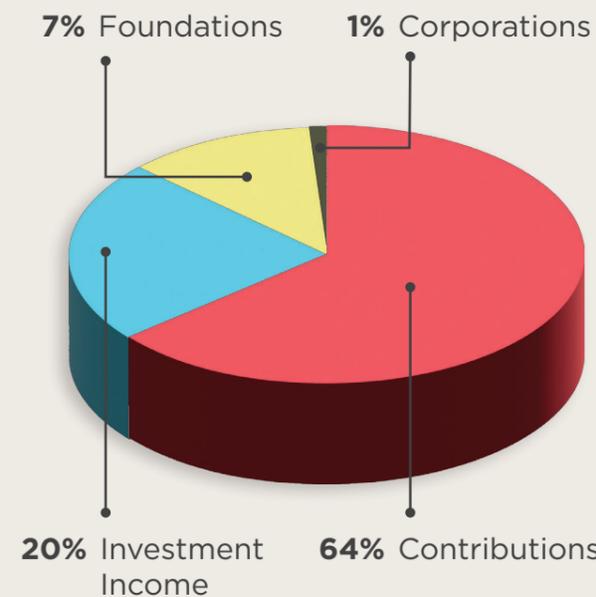
To view our 990 and complete audited financial statement, visit FightEHE.org/financial-information

Independently audited by:
Taylor, Roth And Company, PLLC
Certified Public Accountants
Denver, Colorado

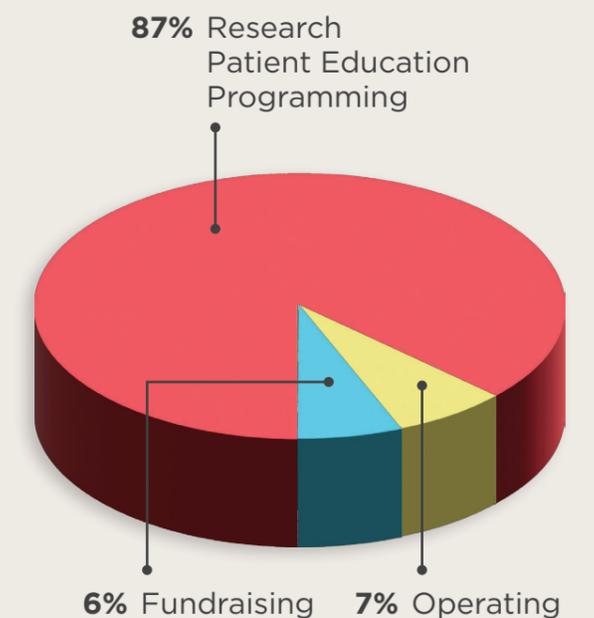
Statement of Activities

	2023		
	Without Donor Restrictions	With Donor Restrictions	Total
<u>Revenue and other support</u>			
Contributions	\$ 298,978	\$ -	\$ 298,978
Investment income	110,378	-	110,378
Foundations	40,494	15,000	55,494
Corporations	4,939	-	4,939
Reimbursements	-	-	-
Net assets released from restrictions	90,000	(90,000)	-
Total revenue and other support	544,789	(75,000)	469,789
<u>Expense</u>			
Program services	485,379	-	485,379
Supporting services			
Management and general	34,759	-	34,759
Fundraising	35,256	-	35,256
Total expense	555,394	-	555,394
Change in net assets	(10,605)	(75,000)	(85,605)
Net assets, beginning of year	1,489,096	322,100	1,811,196
Net assets, end of year	\$ 1,478,491	\$ 247,100	\$ 1,725,591

Revenue & Support



Expenses



THE EHE FOUNDATION
FightEHE.org

As the world's leading patient advocacy and research organization for epithelioid hemangioendothelioma (EHE), The EHE Foundation is dedicated to funding groundbreaking research and fostering collaboration among patients, caregivers, clinicians, researchers, and industry professionals. Together, we are united by a shared vision: a future where EHE is easily diagnosed and effectively treated.

Your generous support can make a profound difference. By contributing to the mission of The EHE Foundation, you join us in working toward a future filled with scientific breakthroughs and improved outcomes for all EHE patients. Together, we can bring hope and a brighter tomorrow to those affected by this ultra-rare disease.



GIVE GENEROUSLY TODAY.