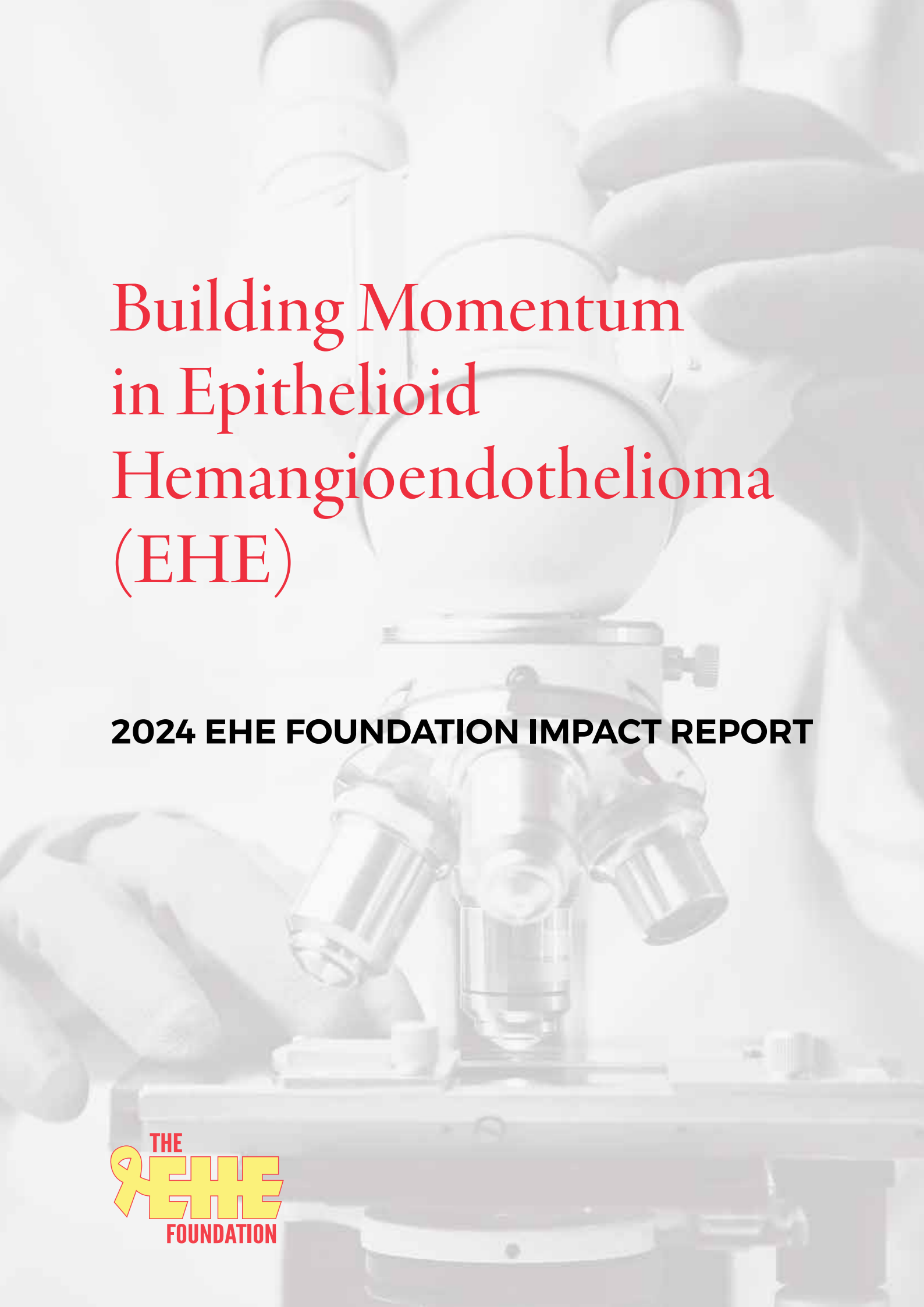




Building Momentum in Epithelioid Hemangioendothelioma (EHE)

2024 EHE FOUNDATION IMPACT REPORT

Dedication

In Memoriam



Amy Baghdadi, J.D.

1972 ~ 2024

We celebrate the life and contributions of Amy Baghdadi, a dedicated member of the EHE Foundation's Board of Directors from 2021 to 2024. Diagnosed with EHE in 2010, Amy underwent a living donor liver transplant in 2011. Throughout her EHE journey, she was a powerful advocate, both personally and professionally, lending her talents to ensure the growth and sustainability of the EHE Foundation.

A passionate champion for EHE research, Amy worked wholeheartedly to ensure a better future for everyone affected by this disease. She gave her time selflessly, leading with kindness, conviction, and an unwavering dedication to progress. Her impact on the EHE community is profound, and her legacy will continue to inspire our mission to find effective treatments and a cure for EHE.

It is with profound respect and gratitude for Amy, her family, and her community that we dedicate this Impact Report to her memory.

Table of Contents

3	Message From the Executive Director
5	About the EHE Foundation
7	Driving Momentum in EHE Research
8	Research Grants Program
11	Collaborative Research & Advocacy
15	Patient-Powered Momentum
16	EHE Global Patient Registry
17	EHE Biobank
21	Building Momentum Through Knowledge
23	EHE 360 Global Patient Conference
27	Fueling Momentum With Generosity
29	EHE Fun Run & Walk
31	EHE Foundation Leadership & Advisors
33	Financials

A Message from the Executive Director



Denise Robinson

Executive Director
& Director of Research

It is an honor to present the 2024 EHE Foundation Impact Report to our community. Each person we touched last year, those who touched us, and so many around the world who share our vision to cure EHE, together made our mission stronger.

We are proud to share the progress made in 2024, including significant momentum in research, growth in global advocacy, and perseverance in clinical science that will ultimately improve lives. The EHE research landscape has expanded exponentially, with breakthroughs on the horizon in early-stage clinical development, drug repurposing initiatives, and catalytic growth in translational research.

Each advancement in knowledge and science brings an opportunity for improved treatments and better outcomes for people with EHE.

‘Patient-powered research’ was more than a phrase in 2024—it became a catalyst for progress. People diagnosed with EHE shared their medical journeys in the EHE Global Patient Registry, donated tumor tissue to the EHE Biobank, and shared their life challenges to inform research. Each contribution is heroic, helping others today and those who will be diagnosed tomorrow. We are deeply grateful to these heroes for advancing research and improving lives.

Education and support remained top priorities, empowering patients and families, care teams, and the research community. Patients face difficult care decisions while enduring the emotional and physical burdens of EHE; clinicians confront a heterogeneous disease without guidelines and sometimes limited access to treatments; researchers pursue novel therapeutic approaches, leaving no stone unturned.

I invite you to explore our progress and read about the many champions for EHE. This progress is made possible by a strong patient community—the heartbeat of everything, the dedicated support of passionate and talented volunteers, our medical, scientific, and strategic advisors, our partners in advocacy, compassionate clinicians, and brilliant researchers. And, importantly, donors, who sustain our mission and momentum.

I am deeply grateful for the opportunity to serve this community, leading our commitment to creating a better future for people diagnosed with EHE.

Sincerely,

A handwritten signature in black ink, appearing to be 'DR' followed by a flourish.

Denise Robinson





The EHE Foundation is the leading global nonprofit organization dedicated to improving the lives of people affected by epithelioid hemangioendothelioma (EHE), an ultra-rare vascular cancer.

We are mission-driven to unlock answers and discover better, more effective therapies. By funding groundbreaking research, equipping patients with knowledge and support on their journey, and harnessing a strong, global collaborative network, we are building real momentum in a community that is in urgent need of breakthroughs.

One in a Million

Epithelioid Hemangioendothelioma (EHE)

EHE is an ultra-rare and unpredictable vascular sarcoma found in less than one in a million people.

With no standard of care, approved treatments, or cure for EHE, the needs of patients are urgent. Because of its rarity and highly variable clinical course, treatment decisions are complex and individualized. Patients are navigating difficult treatment choices alongside their care teams, while enduring symptoms and psycho-social effects of the disease that impact their quality of life.



Pictured: J. Ness, S. Stefan, K. Vise, M. Walker, M. Murtagh, R. Harrington, S. Kennedy, D. Filiatrault, C. Gegel, A. Liebert, T. Scott, C. Nuñez, L. Piazza

The EHE Foundation
replaces fear with knowledge,
isolation with connection,
and uncertainty with hope.

Driving Momentum in EHE Research



Pictured: C. Giani, D. Robinson, P. Pantziarka, S. Stacchiotti, H. Leonard, L. D'Ambrosio, A. Merlini

Investing in a Better Future for People With EHE

Accelerating EHE science is at the heart of the EHE Foundation's mission. By strategically investing in bold, innovative projects, we are creating momentum in the global research landscape and driving progress toward treatments and a cure for EHE.

By uniting world-class researchers, clinicians, and industry experts, and **elevating patients' voices at every step**, we are fueling progress from research breakthroughs to real treatment options and hope for a better future for people diagnosed with EHE.

“EHE research gives me hope that one day, there will be a cure for EHE and that someone newly diagnosed can feel confident in their journey.”

~Leah Holubowski, EHE Patient

Research Grants Program

A Cornerstone of Progress

At the center of the EHE Foundation's research portfolio is the EHE Foundation Research Grants Program—the largest dedicated funding source for EHE research worldwide. With more than \$2 million invested to date, the program fuels high-impact projects across basic, translational, clinical, and psychosocial research, accelerating the development of effective treatments and improving patient outcomes.

\$2.4M

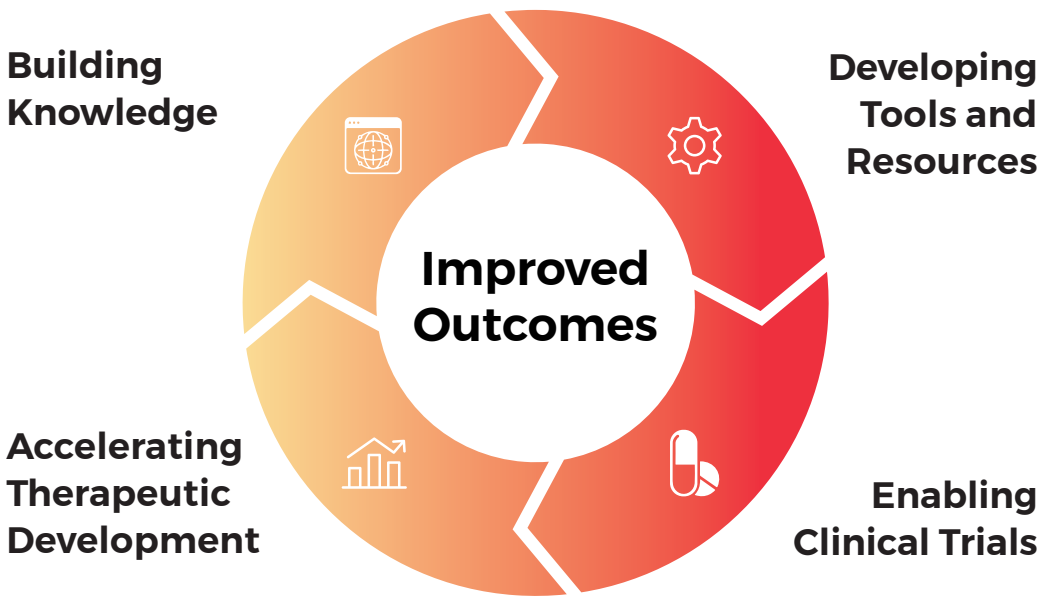
Invested into
high-impact
EHE research

18

Projects funded
in world-class
labs around the
globe

21

Publications
highlighting
new scientific
findings



FUEL THE MOMENTUM TO IMPROVE OUTCOMES

Research Grants Awarded in 2024

Evaluation Of Druggable Targets for the Treatment of Aggressive Metastatic EHE

Principal Investigator: Ajaybabu Pobbati, PhD | Cleveland Clinic Foundation

Award Amount: \$130,000

This translational project aims to improve outcomes for people with aggressive, metastatic EHE by repurposing a drug that can reduce the disease burden. The goal is to establish data that will lead to a clinical trial, bringing new therapeutic opportunities to EHE patients.

In 2022, the EHE Foundation awarded Dr. Pobbati a grant of \$65,000, primarily driven by community fundraising efforts. That seed grant, followed by a \$30,000 extension in 2023, generated promising data on cyclin-dependent kinase inhibitors (CDKIs) as potential treatments for aggressive EHE. Building on this work, Drs. Pobbati and Brian Rubin successfully secured a two-year \$225,000 NIH grant in 2024 to further investigate CDKIs for EHE. What began with grassroots donations has evolved into a powerful investment in cutting-edge research, demonstrating how community-driven funding can spark breakthroughs and pave the way for future therapies.



“Our NIH grant would not have been possible without earlier seed funds from the EHE Foundation’s research grants, an investment made possible by the generosity of the EHE community, which is paying off!”

~Ajaybabu Pobbati, PhD

Bold actions to improve lives.

Combination Therapy Targeting Genomic and Signal Transduction Vulnerabilities in Epithelioid Hemangioendothelioma

Principal Investigator: Gillian DeWane, PhD | University of Iowa Carver College of Medicine

Award Amount: \$97,400

This translational project investigates the utilization of a combination therapeutic approach to sensitize EHE cells when treated with inhibitors targeting TEAD and the PI3K pathway. These results could accelerate the development of targeted therapies, a significant need for people with aggressive EHE.

Characterizing Cell-Penetrating Peptide Entry Into EHE

Principal Investigator: Tohru Yamada, PhD | University of Illinois Chicago

Award Amount: \$80,000

This early-stage translational science proposes a novel strategy to investigate whether a safe cell-penetrating peptide, p28, which is preferentially taken up by many cancer cells, can stabilize p53 in EHE cells with CDKN2A mutation. The scientists hypothesize that this approach should reduce the growth potential of these more aggressive EHE cells, potentially leading to new treatments that improve outcomes for people living with EHE.

Fellowship Travel Grants

In 2024, we were honored to support professional growth and collaboration opportunities for young investigators and nominated scientists, enabling them to participate in impactful scientific conferences that align with our mission. Recipients were:

Sandro Pasquali, MD, PhD | Fondazione IRCCS Istituto Nazionale dei Tumori

Participation in “YAP/TAZ and TEADs: At the Crossroads of Cancer” Workshop | Telluride, Colorado

John Lamar, PhD | Albany Medical College

Participation in “Hippo Pathway in Biology and Diseases” Conference | Melbourne, Florida

Collaboration Drives Progress

Global Partners in Our Mission

Harnessing collaboration drives momentum and accelerates progress. As professional advocates, we aggressively seek collaborative opportunities to advance EHE research and sarcoma science to improve patients' lives.



The **Cleveland Clinic Central Biorepository** partners with the EHE Foundation, providing laboratory analysis, processing, and storage of biospecimens collected in the EHE Biobank. An expert team, including Dr. Brian Rubin, provides project support for each specimen donated.



Health-related quality of life measurement strategy for solid rare cancers

Olga Husson, PhD, and Winette van der Graaf, MD, PhD | The Netherlands Cancer Institute



This multi-national study aims to evaluate how health-related quality of life is assessed in rare cancer patients to develop a measurement strategy for future research and clinical practice. The EHE Foundation was included as a study collaborator, inviting patients to join the study.



Pushing Ultra-rare Sarcoma Beyond Hope

The PUSH Project unites clinicians, scientists, and advocates to build a global data platform that will learn from every patient's treatment experience to inform new therapies, improve outcomes, and enhance quality of life for ultra-rare sarcomas, including EHE.



The **European Medicines Agency** and the **European Organisation for Research and Treatment of Cancer** launched a series of multi-stakeholder workshops on soft tissue and bone sarcomas, using ultra-rare sarcomas as a model for developing new treatments. The EHE Foundation participates with our global EHE advocacy partners to ensure the EHE patient voice is represented in these critical discussions that shape the future of ultra-rare sarcoma treatment.



The EHE Foundation supported a multi-tumor project led by the **Massachusetts Institute of Technology** and the **Rare Cancer Research Foundation**, 'Partnering with Patients to Create a Rare Soft Tissue Sarcoma Functional Genomics Platform as a Community Resource' by contributing de-identified specimens from the EHE Biobank. This project leverages the power of patient-partnered research to develop a platform for discovering rare cancer drug targets.



As part of the **Chan-Zuckerberg Initiative (CZI) Rare As One** program, CZI has provided the EHE Foundation with funding, training, community mentorship, and capacity-building services to support the establishment of a network of researchers and clinicians, convene our community, and develop and advance a research agenda.



The **Transformative Rare Cancer Initiative** at Fred Hutch Cancer Center is a drug-matching platform that utilizes artificial intelligence to help researchers, clinicians, and, most importantly, patients discover additional uses for drugs that have already undergone clinical trials and received FDA approval. Tissue samples from the EHE Biobank are being used to help identify potential therapies for EHE.



SARC is a partner in advocacy and sponsors of important clinical trials that unite sarcoma physicians to advance new treatments and improve outcomes for sarcoma patients, including SARC033, a Phase II clinical trial of trametinib in EHE.



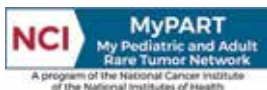
The EHE Foundation is proud to stand alongside the **Sarcoma Foundation of America**, a leading advocacy organization supporting all sarcomas through funded research, advocacy, and public policy initiatives.



C-Path CURE Drug Repurposing Collaboratory harnesses real-world data of off-label prescriptions to advance drug repurposing.



The **National Organization for Rare Disorders (NORD)** hosts the EHE Global Patient Registry on its IAMRARE® platform. The EHE Foundation works as an advocacy partner in NORD's Rare Cancer Coalition.



As an advocacy partner in the **NCI MyPART Network**, the EHE Foundation bridges patients and researchers, helping share experiences and expertise to improve outcomes for people with rare tumors.



The EHE Foundation participated in the user-testing and launch of an online platform developed by the Food and Drug Administration and the National Institutes of Health, designed to share novel uses of existing drugs (drug repurposing).



A powerful alliance providing resources, support, and empowerment to rare disease communities.

Advancing hope, globally.

Projects in Progress

Seeking Advancements in EHE Science

Research grant awards often span years to glean progress. These projects remain ongoing - fueling hope for breakthroughs. The EHE Foundation is committed to these longer-term projects which will improve our understanding of EHE.



TAZ-CAMTA1 Regulation by the Calcium Sensor Calmodulin

(Awarded 2021, planned completion 2024)

John Lamar, PhD | Lamar Lab, Albany Medical College

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

(Awarded 2022, planned completion 2025)

John Lamar, PhD | Lamar Lab, Albany Medical College



The Evaluation of Cytokines and Hormones as Biomarkers for Epithelioid Haemangioendothelioma

(Awarded 2021, planned completion 2027)

- Silvia Stacchiotti, MD | Fondazione IRCCS Istituto Nazionale dei Tumori (INT)
- Prof. Robin Jones | The Royal Marsden
- Paul Huang, PhD | Institute of Cancer Research (ICR)



Creation and Characterization of an EHE Extended Primary Cell Culture

(Awarded 2023, ongoing)

Munir Tanas, MD | Tanas Lab, University of Iowa

Advocacy in Action

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



ESMO 2024 Sarcoma and Rare Cancers Congress

European Society for Medical Oncology
Lugano, Switzerland; March

PUSH Consortium

Pushing Ultra-Rare Sarcoma Beyond Hope
Lugano, Switzerland; March

ASCO 2024 Annual Meeting

American Society of Clinical Oncology
Chicago, IL, USA; May-June

SARC Semi-Annual Meeting

Sarcoma Alliance for Research Through Collaboration
Chicago, IL, USA; May

CTOS 2024 Annual Meeting

Connective Tissue Oncology Society
San Diego, CA, USA; November

EHE Organizations Around the World

The EHE Foundation works in close alignment with a network of EHE advocacy organizations across Australia, Canada, Germany, Italy, and the United Kingdom. Together, these organizations share a unified mission: to improve outcomes for people with EHE worldwide. By collaborating across borders, this global community strengthens the voice of EHE patients, fosters scientific progress, and amplifies awareness of this ultra-rare cancer.



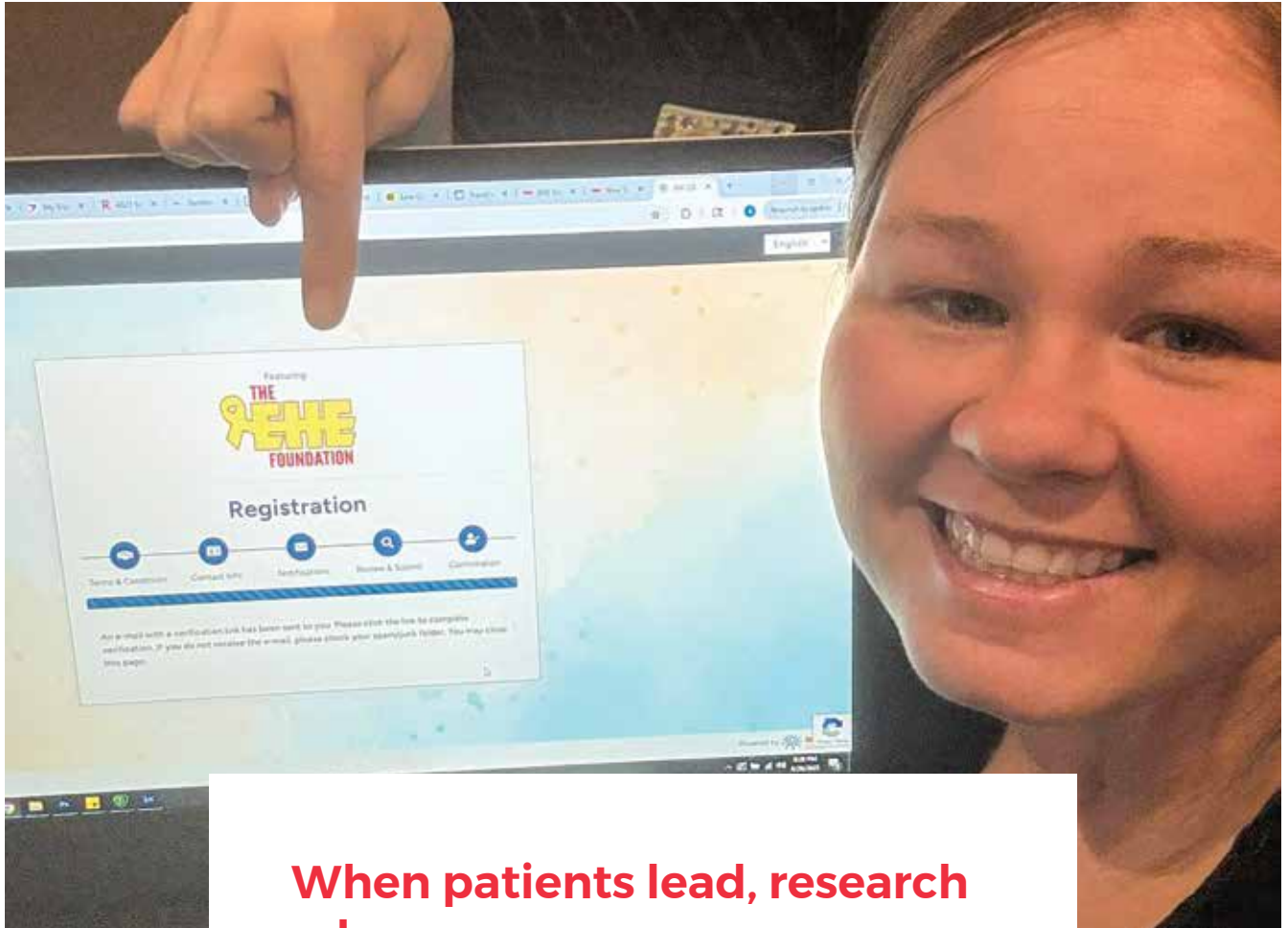
EHE Canada



EHE Germany



Patient-Powered Momentum



When patients lead, research advances.

Advancing EHE research relies on the participation of individuals affected by the disease. No one is better suited to inform our understanding of this disease than the people affected by it. The EHE Foundation's strategic prioritization of EHE patients' voices ensures that research is grounded in real experiences, accelerating discovery and moving us closer to effective treatments and a cure.



FUEL THE MOMENTUM

with a gift to support the EHE Foundation.

EHE Global Patient Registry

Patients Are the Key to the Cure

The EHE Global Patient Registry (EHEGPR) is a secure, international database where people with EHE share their medical histories, treatments, and lived experiences. By gathering patient-reported data in a central, structured repository, the registry aims to become the most comprehensive natural history study of EHE.

For patients, contributing to the EHEGPR is a powerful way to directly influence research and accelerate progress toward future therapies. Data from the registry will help identify clinical trial participants, inform care guidelines, and provide patients with valuable insights by comparing their experiences to those of others living with EHE. Over time, the study aims to guide researchers and clinicians in evaluating treatments and designing stronger, more effective studies.

EHE GPR by the numbers, as of December 31, 2024:

236

people enrolled

29

countries
represented

19%

of participants were
initially misdiagnosed

39%

of participants report
active surveillance as
management

31%

of people who
reported an
intervention, had
surgery

18%

of people reported
using pain
management

“*Participating in the Registry is something that I can do. I’m not a scientist, I can’t study EHE, but I can help the people who are studying this disease find treatments for all of us.*”

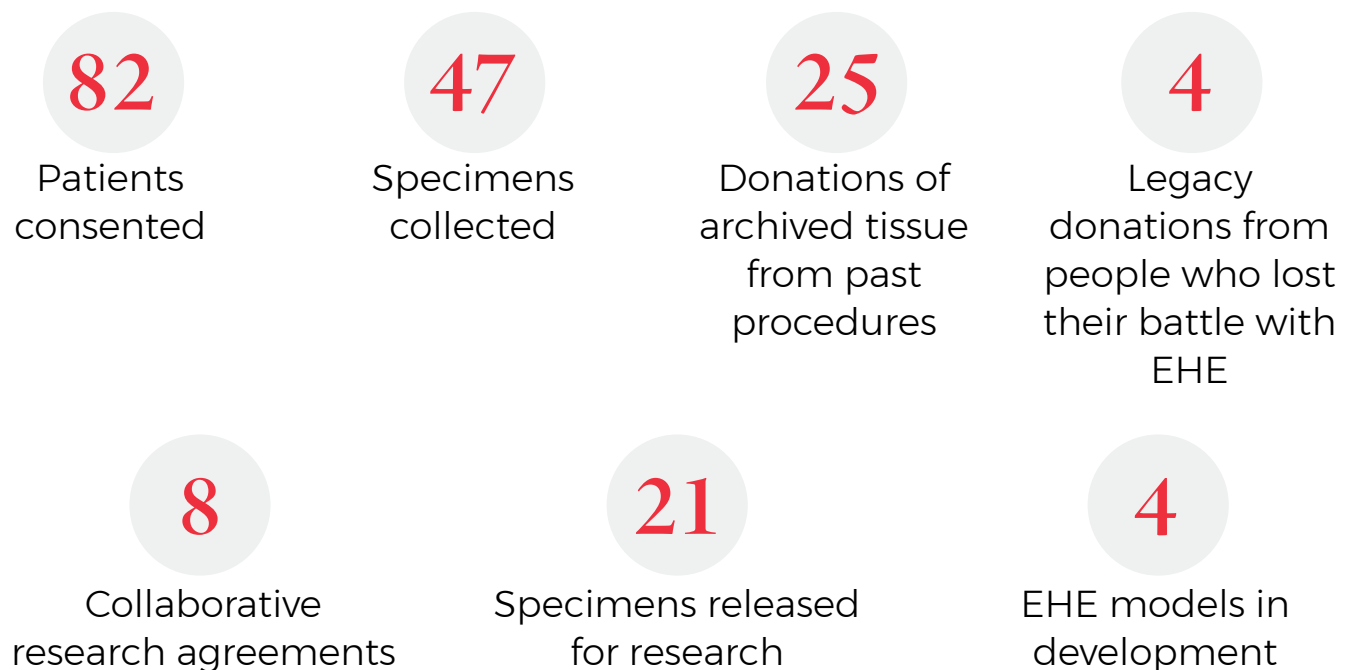
~ Ashley Wibbenmeyer, EHE Patient (pictured opposite)

EHE Biobank

Accelerating Basic and Translational Science

The EHE Biobank is a centralized, patient-contributed collection of fresh tissue and fluid samples taken during surgeries or procedures. These invaluable specimens power the development of disease models, support research into EHE's biology and biomarkers, and deepen our understanding of how the disease manifests differently across individuals and tumor sites. By choosing to donate, each participant plays a direct role in accelerating scientific discovery and guiding future treatment approaches.

EHE Biobank by the numbers:



“*Every specimen is rare. Every specimen is generously given by someone in great need of care. We are deeply grateful to the people who have donated their specimens to the EHE Biobank, giving selflessly to help others.*

~ Denise Robinson, EHE Foundation Executive Director and Director of Research

Observational Study

The EHE Foundation has partnered with **xCures** to transform patient medical records into structured, regulatory-grade data. This information enables scientists and clinicians to better understand the natural history of EHE, identify best practices, and explore effective treatment options. By powering registries and natural history studies, these efforts accelerate research and can support clinical trials that bring promising therapies closer to approval.

Clinical Trials for EHE

Patient-centered Clinical Development

As advocates, we partner with academic and commercial researchers to ensure that patient perspectives are heard and understood. By sharing insights from lived experiences, we inform the development of clinical trials in ways that can make them more relevant and accessible, with the goal of improving participation and outcomes for people with EHE.

TEAD Inhibitors for EHE

TEAD inhibitors are a promising class of drug that holds significant hope for EHE patients and many other cancers. These small molecules target the Hippo signaling pathway, which plays a crucial role in cell growth and proliferation. In 2024, multiple entities announced studies or were in clinical-stage development.

Sponsor	Study Title	Identifier
Novartis Pharmaceuticals	A Phase I Study of IAG933 in Patients With Advanced Mesothelioma and Other Solid Tumors	NCT04857372
Vivace Therapeutics, Inc.	Study to Evaluate VT3989 in Patients With Metastatic Solid Tumors	NCT04665206
Ikena Oncology*	Oral TEAD Inhibitor Targeting the Hippo Pathway in Subjects With Advanced Solid Tumors	NCT05228015
SpringWorks Therapeutics	SW-682 in Advanced Solid Tumors	NCT06251310

*Program discontinued May 2024

The drug development pipeline is growing, and the EHE community is research-ready.

Other Impactful Studies

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

This 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, clarify the activity and efficacy of currently available treatment options, and describe treatment patterns. Study Identifier: NCT06408441.

Epithelioid Hemangioendothelioma Observational Study

An observational study of patients with EHE that aims to better understand the natural history of the disease, treatment outcomes, identify cytokines and hormones as biomarkers of disease, and generate pre-clinical models to assess the activity of anticancer agents and validate novel therapeutic targets. This study is sponsored by Fondazione IRCCS Istituto Nazionale dei Tumori, Milano. Study Identifier: NCT06680401.

Health-related Quality of Life Measurement Strategy for Solid Rare Cancers

A multi-national study that aims to identify and examine how health-related quality of life (HRQoL) is currently assessed in rare cancer patients and to develop a HRQoL measurement strategy that could be applied in future research and clinical practice. This study is funded by the European Organization for Research and Treatment of Cancer Quality of Life Group.
<https://doi.org/10.1016/j.rare.2023.100012>.

Patients who volunteer for research studies are heroes for everyone diagnosed with EHE. We are grateful to patients and their families, as well as the doctors and researchers who make opportunities to advance EHE research possible.

Published Research

The EHE Foundation champions patients, advocates, clinician scientists, and researchers to grow our knowledge in EHE science. The EHE Library is a central source for knowledge and hope.

Publication Spotlight: Elevating Patients' Voices



Championed by patient advocates in collaboration with clinical experts, an impactful publication in *Frontiers in Oncology* amplified the voices of EHE patients from around the world. The publication is based upon a survey evaluating 129 patient responses from 21 countries, collecting patients' perspectives and experiences regarding the use and accessibility of sirolimus. This study puts patients' voices front and center as we work toward regulatory approval of sirolimus for EHE, further ensuring patients have equitable access to effective treatment.

Other Publications from 2024

A single-arm phase 2 trial of trametinib in patients with locally advanced or metastatic epithelioid hemangioendothelioma. *Clinical Cancer Research* 30.20 (2024): 4584-4592. Schuetze, S., et al.

Analysis of Blood-Based Biomarkers as Prognostic Factors in Patients with EHE Treated with Trametinib in SARC033. CTOS 2024 Poster Presentation. Schuetze, S., et al.

GDF-15 Predicts Epithelioid Hemangioendothelioma Aggressiveness and Is Downregulated by Sirolimus through ATF4/ATF5 Suppression. *Clinical Cancer Research* 30.22 (2024): 5122-5137. Stacchiotti, S., et al.

Irreversible Electroporation as a Valid Treatment Option for Hepatic Epithelioid Hemangioendothelioma: An International Multicenter Experience. *CardioVascular Interventional Radiology* 47, 883-890 (2024). Narayanan, G., Spano, A., Gentile, N., et al.

The observational EURACAN prospective clinical registry dedicated to epithelioid hemangioendothelioma: The protocol of an international and collaborative effort on an ultra-rare entity. *PLOS one* 19.8 (2024): e0308387. Frezza, A., et al.

Epithelioid hemangioendothelioma (EHE) with WWTR1::TFE3 gene fusion, a novel fusion variant. *Genes, Chromosomes and Cancer* 63.2 (2024): e23226. Li, S., et al.

CDK9 inhibition by dinaciclib is a therapeutic vulnerability in epithelioid hemangioendothelioma. *Clinical Cancer Research* 30.18 (2024): 4179-4189. Pobbati, A., et al.

Is It Time to Resist Using RECIST as a Primary Endpoint for Rare Tumor Trials? *Clinical Cancer Research* 30.20 (2024): 4552-4553. Van Tine, B. and Haarberg, S.

Short-term outcomes of combined therapy with sirolimus and interferon-alpha 2b for advanced hepatic epithelioid hemangioendothelioma. *Therapeutic Advances in Medical Oncology* 2024;16. doi:10.1177/17588359231220509. Liu X., Zhou R., Liu L., et al.

Building Momentum Through Knowledge



Global education leading to improved outcomes.

Knowledge is powerful when facing a diagnosis as rare and unpredictable as EHE. The EHE Foundation equips patients, their families, and healthcare professionals with the necessary resources to navigate care with confidence.

Through education, we empower strong, patient-centered care teams to make informed care decisions, looking ahead with hope.



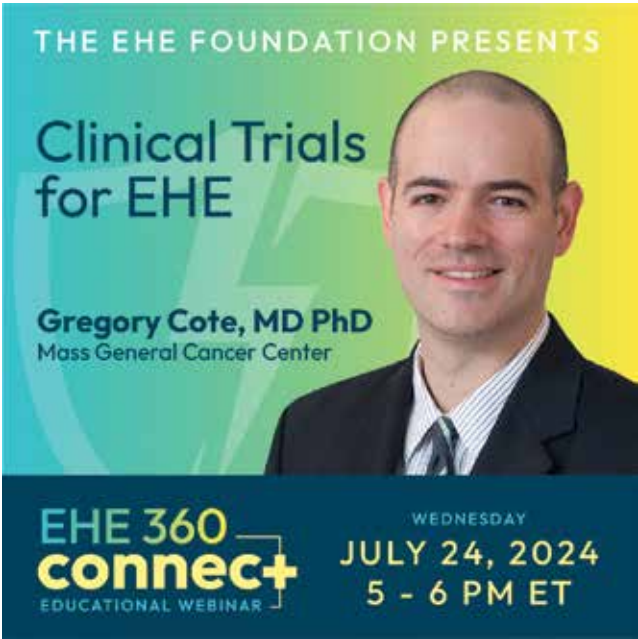
FUEL THE MOMENTUM

with a gift to support the EHE Foundation.

Community Programming



EHE 360 Connect bridges patients, scientists, and clinicians as partners in our mission. Through deep learning and meaningful engagement, education brings people together, fostering connection and collaboration among all EHE stakeholders.



By deepening social bonds and strengthening feelings of belonging, EHE Community Connections creates meaningful opportunities for the EHE community to come together. Multifaceted discussions explore research participation, caregiving, anxiety, and isolation—key elements in building resilience and improving lives within a strong community.



EHE 360 Global Patient Conference

Empowering Patients Through Education

Uniting patients, caregivers, clinicians, and researchers from around the world, this annual, virtual convening features global leaders in EHE science and clinical care, empowering attendees with the latest EHE research and treatment options.

Held during EHE Awareness Month on April 19, 2024, the 2024 EHE 360 Global Patient Conference marked the fourth annual gathering of leading EHE experts. What began in 2021 as a small scientific symposium has since grown to include patients and caregivers, evolving into the premier global event for EHE science, education, and collaboration.



260+

Registrants



25

**Countries
Represented**



934+

**Event Recordings
Viewed**



6

**Hours of
Educational
Content Shared**

“*This event shows how many people are affected by this disease and how committed people are. We are not alone!*”

~ Beth Tracy-Kaliski, 2024 EHE 360 Conference Attendee

Conference Presenters



Brian Rubin, MD, PhD
Cleveland Clinic
EHE 101: What You Need to Know



Denise Robinson, Principal Investigator, Director of Research
EHE Foundation
A Community Update on the EHE Global Patient Registry



Nadia Zaffaroni, PhD
Fondazione IRCCS Istituto Nazionale dei Tumori di Milano
Identification of Biomarkers for EHE to Inform Patient Management and Potential Therapeutic Targets



Ajaybabu Pobbati, PhD
Cleveland Clinic
Targeting EHE: Pocket Science and Other Approaches



Fiona Ross, Board of Directors
Sarcoma Cancer Foundation of Canada
ProCARE Canada Research Update



Tom Wei-Wu Chen, MD, PhD
National Taiwan University Hospital
Myth Buster: A Medical Oncologist's View on the Management of EHE



Pan Pantziarka, PhD
Anticancer Fund
Drug Repurposing: Emerging Opportunities to Identify Treatments for EHE



Hugh Leonard, Chair of Trustees
EHE Rare Cancer Charity (UK)
EHE European Research Collaboration



Andrei Ivanescu, President
EHE ITALIA Associazione Non Solo Laura ODV
EHE ITALIA

Ask the Expert Panel



Elizabeth Davis, MD
Vanderbilt University Medical Center



Melissa Burgess, MD
UPMC Hillman Cancer Center



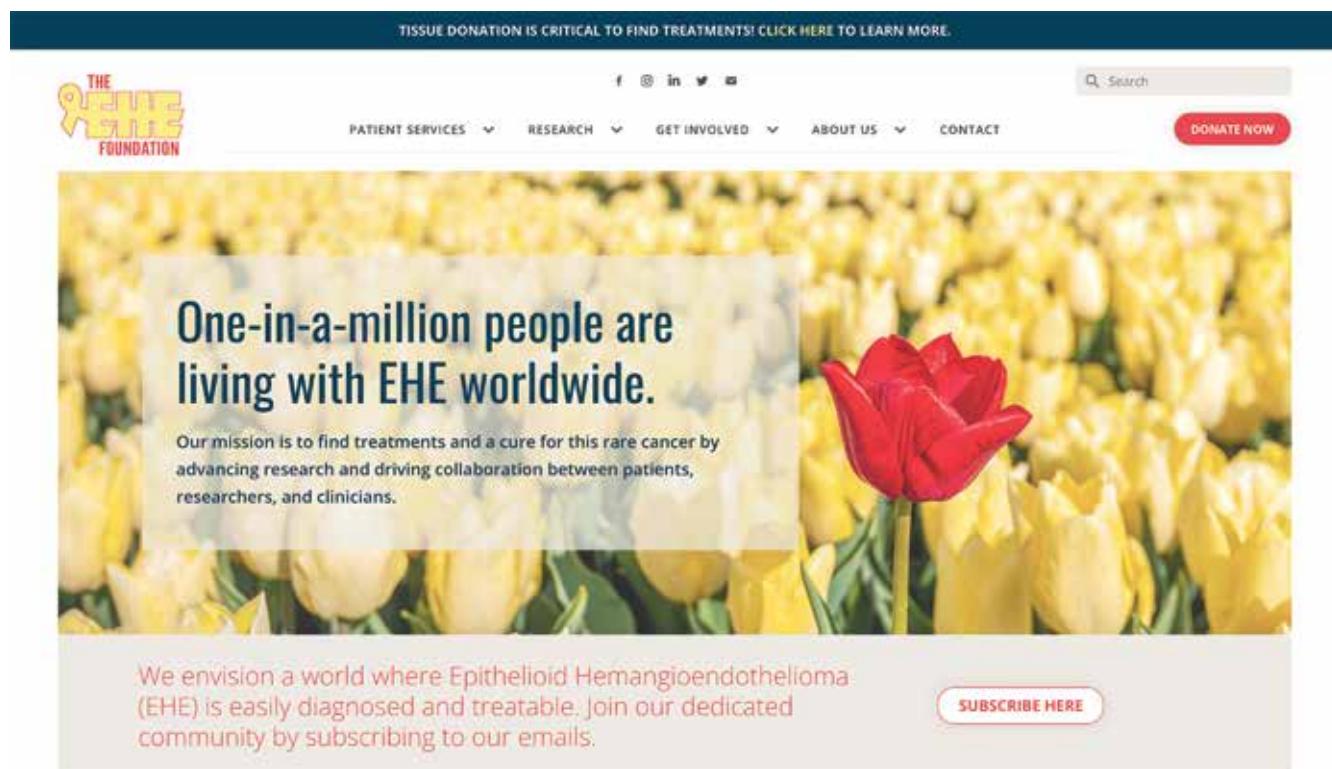
Rashmi Chugh, MD
University of Michigan Health Rogel Cancer Center



William Tap, MD
Memorial Sloan Kettering Cancer Center

FightEHE.org

FightEHE.org, the online home of the EHE Foundation, boasts an impressive collection of medically reviewed information, resources, patient stories, and more, designed to help patients and their caregivers navigate their journey from a place of empowerment and knowledge.



70+

Pages of Information



32K

**New and Returning
Visitors in 2024**



141

From 141 Countries

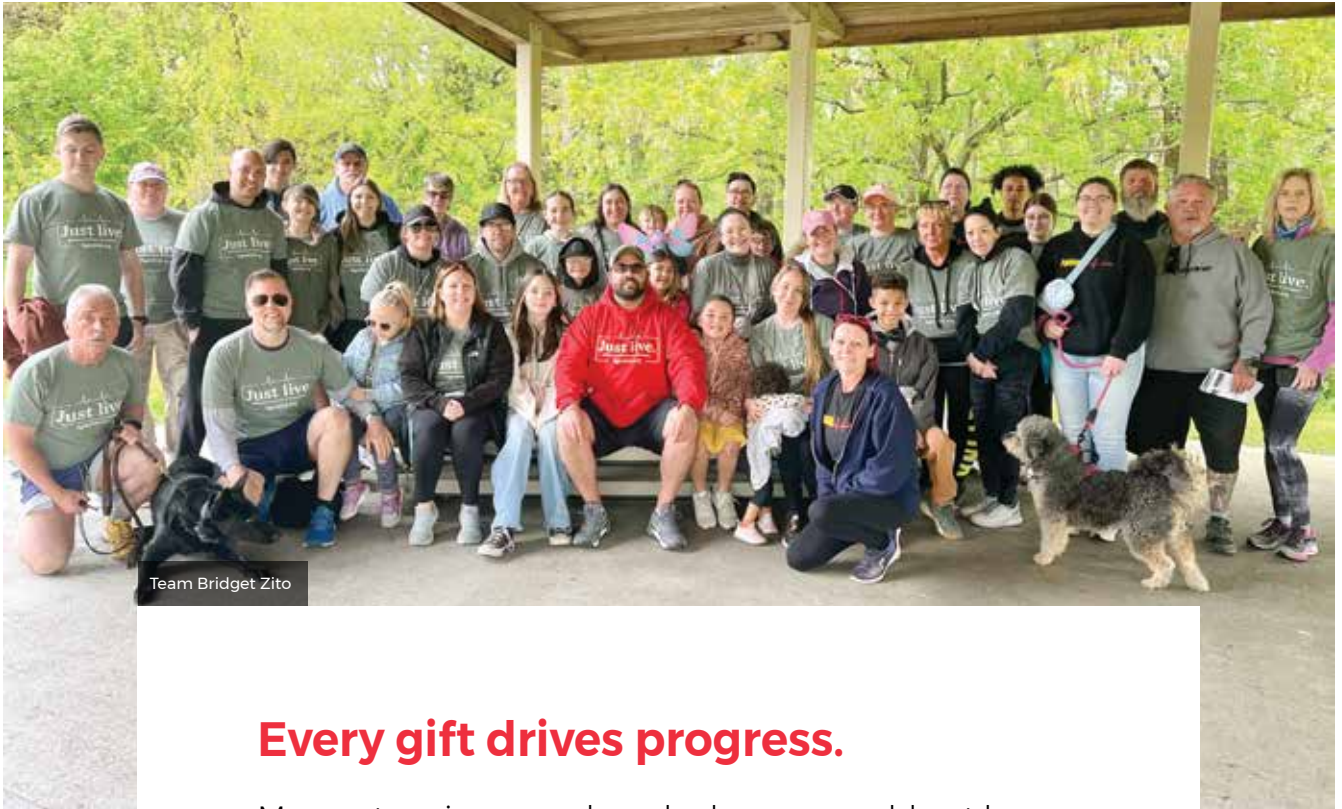
The most comprehensive
source of EHE information.



Justin Darragh

Diagnosed with EHE in 2022, Justin was treated at the University of Michigan Health Rogel Cancer Center, where he underwent multiple surgeries to manage his disease. With his EHE now stabilized and monitored biannually, he set his sights on advancing his education and pursuing his dream of becoming a doctor. In a full-circle moment, Justin returned to the very institution that treated him—this time as a graduate student.

Fueling Momentum With Generosity



Every gift drives progress.

Momentum in research and advocacy would not be possible without the generosity of those who give. Every dollar donated to the EHE Foundation is transformed into progress—funding research, expanding education, and amplifying the voices of people living with EHE.

Together, we are proving that giving creates unstoppable momentum toward a future where EHE is treatable and ultimately curable.

We are deeply grateful for the generosity that fuels our work.



FUEL THE MOMENTUM

with a gift to support the EHE Foundation.

Power in Community

Honoring Loved Ones, Fueling Hope

The EHE community channels love and loss into action, hosting events to raise critical dollars for EHE research while carrying forward the legacies of those they honor. Every event is a testament to the strength of families and their communities, transforming remembrance into momentum.



Big Steve Day (July 2024)

Held at Stony Creek Golf Course in Oak Lawn, Illinois, the second annual Big Steve Day golf tournament memorialized Steve Walsh, Jr. with a day of fun on the links. With over 40 golfers in attendance, this special event brought together family and friends united in their mission to support Steve's legacy, raising \$10,000 for EHE research. We are grateful for their dedication to helping those battling EHE.

10th Annual Holiday Benefit Concert (December 2024)

Incendiary, a hardcore punk band from Long Island, New York, rocked their 10th Annual Holiday Benefit show in honor of their friend Brandon Rabinowitz, who lost his battle with EHE in May 2024. We are grateful to the band and their supporters who generously donated \$10,000 in Brandon's memory.



All in the Family (2024)

PFC Timothy Webb passed away from EHE in April 2019. To honor his memory, his sisters, Rainey and Lucy Sue, hosted fundraisers through their youth groups, raising more than \$1,000 in 2024. Rainey said, "Lucy Sue and I want to help those with the same one-in-a-million cancer that our brother had. We miss him, but we know he would be proud of what we're doing to help the EHE community." We thank Rainey, Lucy Sue, and their youth organizations for memorializing their brother.

EHE Fun Run & Walk

Awareness + Fundraising = Impact

The EHE Foundation is proud to celebrate the eighth successful year of the annual EHE Fun Run & Walk. This event unites families, friends, co-workers, and the global EHE community in an extraordinary way. The 2024 event boasted 1,387 registrants, who stepped up to raise awareness and critical dollars for research, all while having some fun. Individuals and teams donned the Just Live! T-shirts supporting a brighter future for people affected by EHE.

Thanks to the steadfast support of participants, donors, and generous sponsors, we raised over \$73,000, a testament to the incredible things that can be achieved when communities come together.



\$73k+

**Record-breaking
Total Raised for
EHE Research**



32

**Teams Rallied for
People with EHE**



1387

**Registered
Participants**



Team Jennifer Ness



Team Jacob Latch



Leadership

Our core values define our work and strengthen the organization, our community, and ultimately, our mission.

- **Patients are the center of everything we do.**
- Our mission is stronger when we are **inclusive**.
- **Collaboration** is essential for learning and growing.
- **Trust** and **transparency** are required.
- Our **passion** for progress is urgent.
- Challenging norms and chasing **innovation** is required.

Advisory Board

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Director of Development & Communications

Julie Wahl

Finance Manager & Patient Advocate

Patty Cogswell

EHE Biobank Principal Investigator

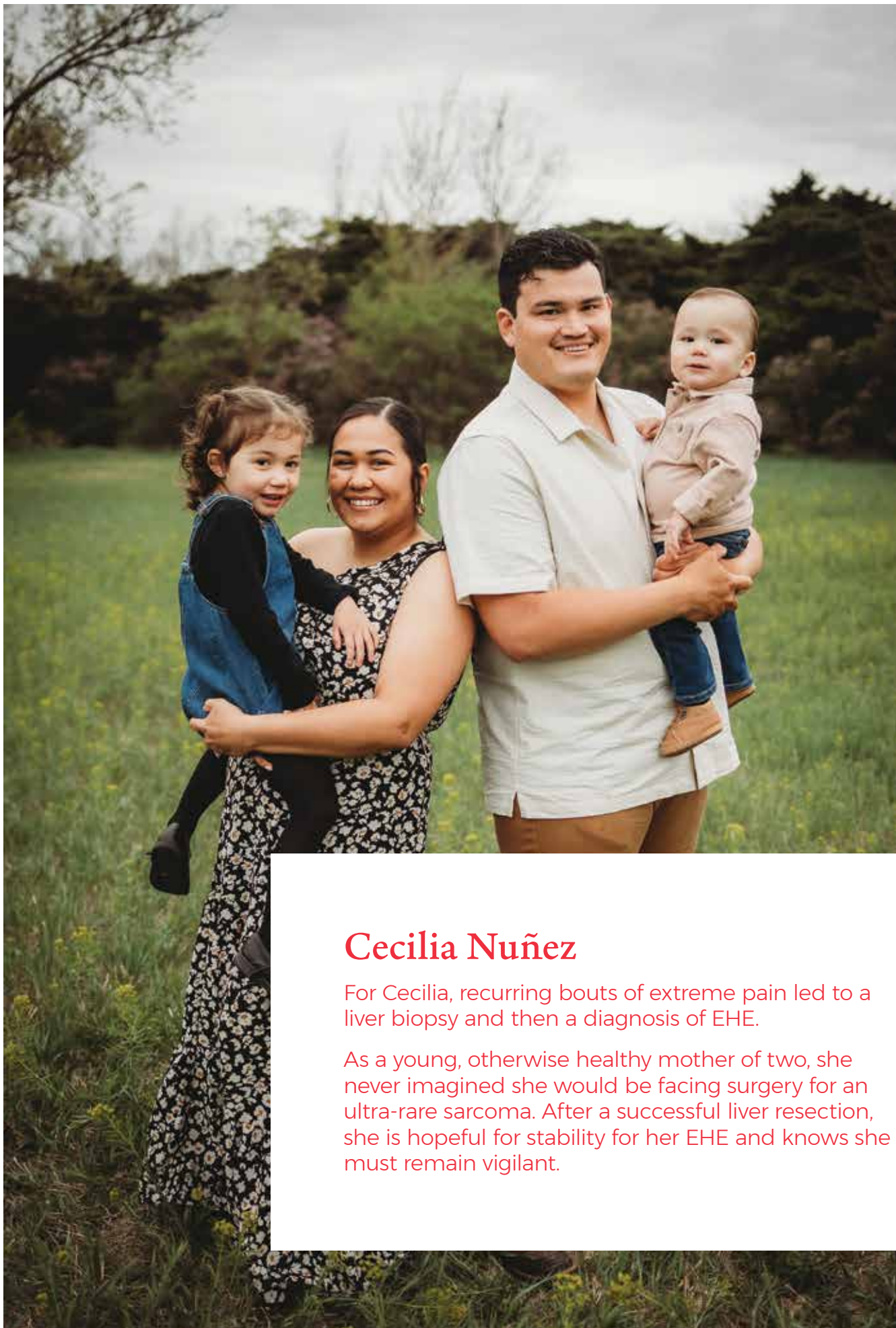
Seth Haddix, PhD

EHE Biobank Coordinator

Sania Choudhary

Junior Research Fellow

We are grateful to the volunteers who amplify our mission by lending their talents and time.



Cecilia Nuñez

For Cecilia, recurring bouts of extreme pain led to a liver biopsy and then a diagnosis of EHE.

As a young, otherwise healthy mother of two, she never imagined she would be facing surgery for an ultra-rare sarcoma. After a successful liver resection, she is hopeful for stability for her EHE and knows she must remain vigilant.

Financials

Statement of Financial Position December 31, 2024

	<u>2024</u>
<u>Assets</u>	
Cash and cash equivalents	\$ 884,568
Contributions receivable	57,857
Grant receivable - multi-year	-
Investments	<u>907,903</u>
Total assets	<u><u>\$ 1,850,328</u></u>
 <u>Liabilities and net assets</u>	
<u>Liabilities</u>	
Accounts payable	\$ 38,876
Grants payable - multi-year	<u>282,900</u>
	<u>321,776</u>
 Net assets	
Without donor restrictions	1,381,452
With donor restrictions	<u>147,100</u>
Total net assets	<u><u>1,528,552</u></u>
Total liabilities and net assets	<u><u>\$ 1,850,328</u></u>

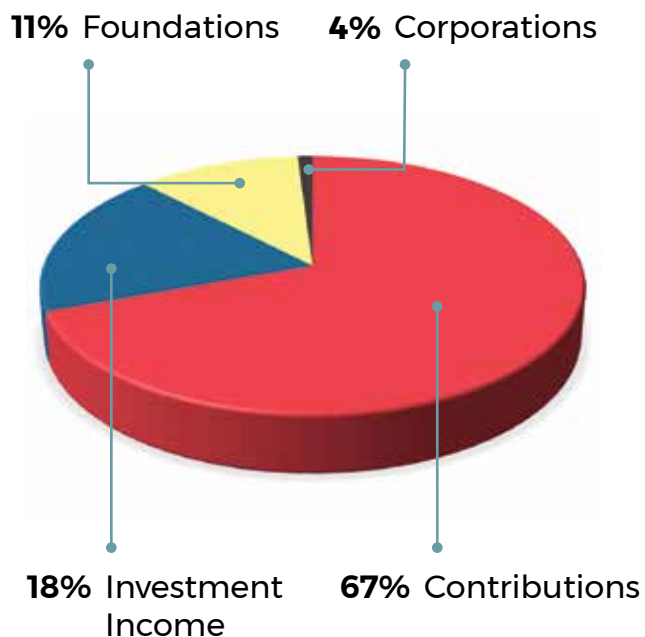
To request our 990 and complete audited financial statement, please email info@fightthe.org.

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

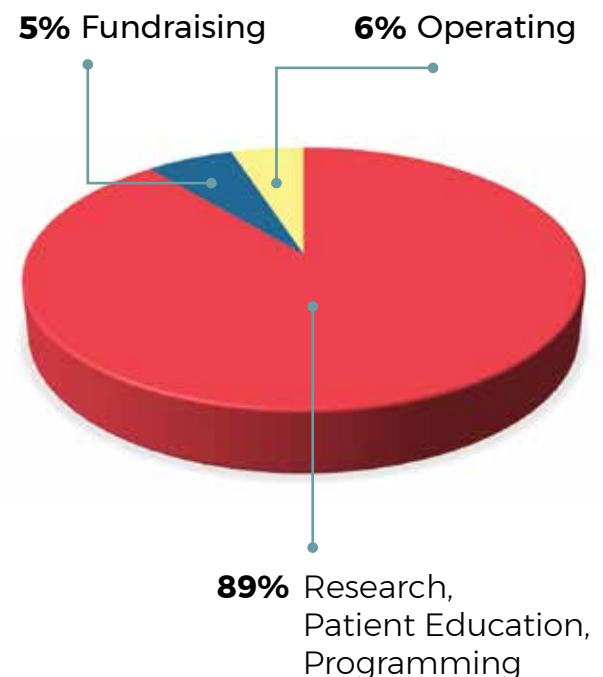
Statement of Activities

	2024		
	Without Donor Restrictions	With Donor Restrictions	Total
<u>Revenue and other support</u>			
Contributions	\$ 403,219	\$ -	\$ 403,219
Investment income, net	110,834	-	110,834
Foundations	69,304	-	69,304
Corporations	26,858	-	26,858
Net assets released from restrictions	100,000	(100,000)	-
Total revenue and other support	710,215	(100,000)	610,215
<u>Expense</u>			
Program services	721,771	-	721,771
Supporting services			
Management and general	41,025	-	41,025
Fundraising	44,458	-	44,458
Total expense	807,254	-	807,254
Change in net assets	(97,039)	(100,000)	(197,039)
Net assets, beginning of year	1,478,491	247,100	1,725,591
Net assets, end of year	\$ 1,381,452	\$ 147,100	\$ 1,528,552

Revenue & Support



Expenses





FightEHE.org

The EHE Foundation is the leading global nonprofit organization dedicated to improving the lives of people affected by epithelioid hemangioendothelioma (EHE), an ultra-rare vascular cancer.

By funding groundbreaking research and equipping patients with education and resources, we are building an empowered collaborative community that is making progress.

Your generous support can make a profound difference in improving outcomes for people diagnosed with EHE.



GIVE GENEROUSLY TODAY.

info@FightEHE.org | 1-877-460-4240 | 1561 Hopi Court, Hobart, WI 54313

The EHE Foundation is a 501(c)(3) nonprofit organization. | Tax ID: 47-3238441