

The Hypertrophic Cardiomyopathy Association Annual Report 2023



**Hypertrophic
Cardiomyopathy
Association**

Serving the HCM Spectrum Disorder Community Since 1996

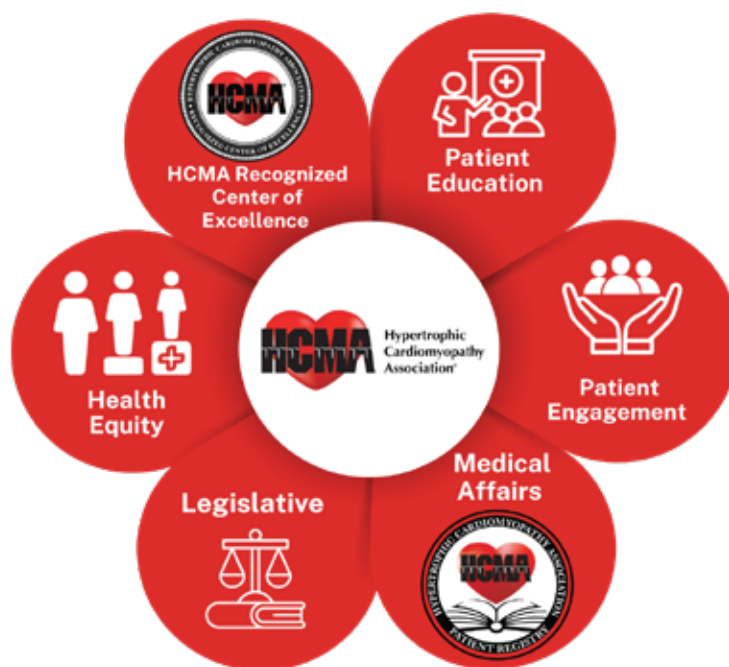
Serving the HCM Spectrum Disorder Community Since 1996

Contents

Founder's Letter	2
The HCMA Team	3
Patient Engagement & Education	4
Centers of Excellence	6
Medical Affairs	7
Legislative	8
Health Equity & International	9
Conferences and Meetings	10
Finances	11
Sponsors and Top Donors	12

The Hypertrophic Cardiomyopathy Association (HCMA) is the preeminent organization improving the lives of those with hypertrophic cardiomyopathy (HCM), preventing untimely deaths, and advancing global understanding. Founded in 1996, we are committed to providing support, education, advocacy and advancing research, understanding and care to those with HCM.

One Mission. Many Programs.





Founder's Letter

Letter from the Founder and CEO, Lisa Salberg

When we began the journey to build the Hypertrophic Cardiomyopathy Association, the world was just learning how to use the internet. It was 1995, and our family had just suffered a devastating loss when my sister died from mismanaged HCM. The world has changed in so many ways over the past 28 years, and the changes within the HCM community are awe-inspiring.

We were once a community of a handful of experts, which required patients to travel thousands of miles for specialized healthcare. We now have 50 HCMA Recognized Center of Excellence programs stretching across the country. We have grown into an organization with nine full-time staff, two part-time staff, multiple contractors, and over a dozen non-profit and industry partners. We continue to amplify the patients' voices through our Ambassador program, discussion groups, Bighearted Warrior tour webinars, and more.

We will continue to grow over the coming years to ensure that support services, education, advocacy, and HCMA Recognized Center of Excellence care is available to all in need. This task will require us all to contribute our time, dollars, and intellect to help solve the problems still facing our community. We must improve the timeliness of diagnosis and access to new and innovative therapies while supporting the newly diagnosed and those managing HCM for the long term.

As a child diagnosed with HCM in 1980, I have seen the best and worst of the healthcare system. I have spent my life trying to improve access to care for all patients with HCM and other forms of genetic heart disease worldwide. I thank you all for being part of this amazing journey. I look forward to continuing our work with you and other collaborators to ensure that families stay whole.

Please contact the office anytime to learn more about our projects and services. Our staff will be more than happy to assist you.

Our Vision

To be the pre-eminent organization improving the lives of those with HCM, preventing untimely deaths, and advancing global understanding.

Our Objectives

- Educate about the symptoms and treatment options for patients, their families and their medical providers.
- Advocate for policy/ legislation that improves disease detection, healthcare access, matters of importance to the community.
- Develop and maintain a network of support for individuals with HCM and their families.
- Increase accessibility to specialized healthcare professionals providing evidence-based treatment of HCM.
- Promote and publish research of HCM and broaden access to results with the ultimate goal of eradicating the disease.
- Partner with complementary organizations that will help further the mission of the education about, and management of the disease.
- Generate appropriate funding for a sustainable organization and ongoing patient and physician engagement.



The HCMA Team

Staff and Contractors

Lisa Salberg

Founder & CEO

Elena Morgan

Assistant Director

Ross Hadley

Project Manager

Stacey Titus

COE Coordinator

Sabrina Cuddy

Intake Coordinator

Julie Russo

Legislative Advocacy/ Volunteer
Coordinator

Linda Montgomery

Patient Advocate-intake

Olivia Esposito

Marketing & Graphics

Carolyn Willis

Membership Coordinator

Julie Olsen

Event Coordinator

Michele Packard- Milam

HCMAI Development

Cody Stubbin

Social Media Coordinator

Nikki Karri

Intern – 2017 - present

HCMA Ambassadors

Maier Bianchi

Mary Ann Daniel

Lauren Donoghue-Cinelli

Ashley Fisher

Joey Graham

Debbie Hamilton

Lekeshia Henderson

Reinhard Kirchhof

Karen Klimczak

Dino Marino

Gwen Mayes

Breanna Restorick

William Rossi

Susan Shapiro

Dominic Venti

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MS, MHS**

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Legislative Advocacy Committee Chair

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Billur Dowse

Bill Rossi

Michael Lynch, MD

Stephen Winters, MD

Emeritus

Lynn Perry

Emeritus

Richard Melia

Emeritus

Discussion Group Leaders

Sabrina Cuddy

Ross Hadley

Karen Klimczak

Greg LeValley

Gwen Mayes

Linda Montgomery

Lynda Neuhausen

Karen L Newstrom

Paul Perlman

Debra Rafson

Trudy Tynan

Sydelle Zinn

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Amy Blair

Rosemary Conlon

Lindsay Davis

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PhD, MS, MHS**

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Aaron Troy

Judith Zerden

Billur Dowse

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Duke Appiah

Milla Arabadjian, PhD

Milind Desai, MD

Martin Maron, MD

Steve Ommen, MD

Mark Rothstein

Mark Zucker, MD

Health Equity

Samantha Antoine

Milla Arabadjian, PhD

Feda Briggs

Alex DeFeria, MD

Melissa Holloway Schmidt

Saba Ilyas

Benjamin Lee

Elizabeth Wessman

Tim Westhaver

Avonne White

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Leigh Bell

Marc Block

Victoria Caragay Wyatt

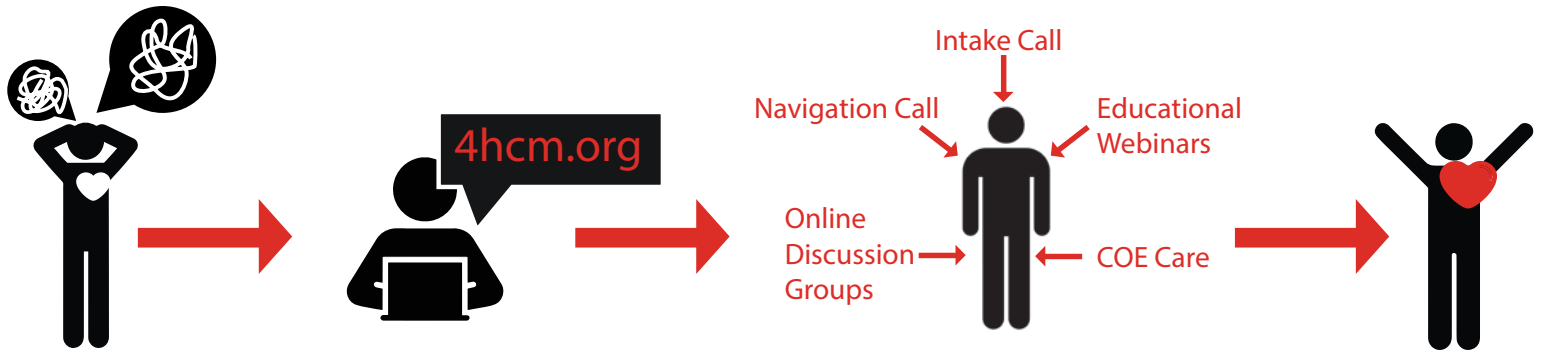
Gordon A. Fox, PhD

Fabian Metayer

Marion Van Sinttruije

Tim Westhaver

Patient Engagement & Education



The HCMA provides one-on-one support to patients through our Intake and Navigation Calls. We collect patients' health histories and help guide them through the decision-making process around medication, surgery, genetic testing, and more. In 2023, we conducted about 1,000 intake and navigation calls and hired a full-time Client Advocate, Linda Montgomery.

The HCMA has an expansive website available for patients with various educational content (4hcm.org). In 2023, we had over 150,000 website visitors with over 1 million engagement events, an increase of 15% engagements over 2022.

HCMA Education and Engagement Programs



The HCMA introduced online patient discussion groups in January 2021. Our discussion groups are designed to share, inform, and support individuals living with HCM. Each monthly discussion group is led by an HCMA-trained volunteer and covers topics such as new diagnosis, heart transplant, ICDs, emotional support, myectomy, and more. In 2023, we hosted 124 discussion groups which had 980 registrants.



Patient Education continues to be core to the mission of the HCMA. The HCMA successfully launched our Bighearted Warrior Tour in 2020. This virtual tour of HCMA COE programs brings together thought leaders in HCM patient care to discuss important topics such as novel therapies, imaging, exercise, surgery, genetic counseling, and more. In 2023, we hosted 14 webinars in this series with over 1200 live participants and over 27,000 total interactions.



In 2023, HCMA launched the Nest Companion, a phone app or website that directs patients to educational content. The Nest Companion makes it easy for patients to identify the specialty care they need based on their personal health information, learn what to expect from screenings and procedures, update their health history information, and access HCMA support services.

Patient Engagement & Education

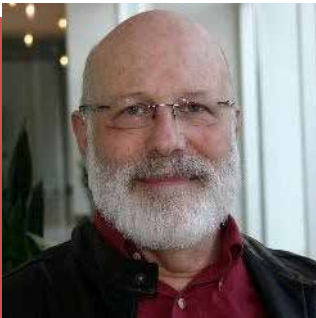


We introduced the new HCMA Ambassador program in January 2023. Fifteen ambassadors spread awareness of HCM using social media. They have learned to optimize their online presence to help people with HCM get an accurate diagnosis, access proper care, and feel less alone by hearing other patients' experiences.



Lisa Salberg, HCMA CEO and Founder, also hosts a weekly podcast that features educational, inspirational, and enlightening discussions with HCM stakeholders. Regularly scheduled co-hosts include Dr. Martin Maron (Lahey Medical Center), Dr. Harry Lever (Cleveland Clinic), and Dr. Steve Ommen (Mayo Clinic). The HCMA Tales from the Heart podcast has had over 16,000 downloads on Podbean and almost 800 hours of view time on YouTube.

We also worked with industry partners Imbria, Bristol Myers Squibb, Cytokinetics, and Tenaya to assist with clinical trial awareness and recruitment for new pharmaceutical and gene therapy options for patients with both obstructive and non-obstructive HCM. We shared these trial opportunities with our patient community through webinars, emails, and social media campaigns.



The past year was the second year of the Patient Education Committee's existence. During this year, we provided assistance to the HCMA office on a number of projects, including the Nest companion. The committee has begun a project aimed at educating patients and caregivers about decision-making for HCM. The first six pieces of written material are in review, and will be published in the HCMA blog. More brief articles will be prepared in the coming months. We have also discussed some initial ideas for a program on basic caregiver education. The committee itself continues to work well: our members all participate and generate quite a few useful ideas. - Gordon A Fox, PhD



HCMA Recognized Centers of Excellence®

The HCMA is committed to helping patients find the best care possible. Our HCMA Recognized Centers of Excellence (COE) are hospitals and clinics with exceptional expertise, volume of care, quality of research, patient communication, patient and medical education, and facilities. To date, 50 Centers have been recognized, including the addition of two new centers in 2023. The latest centers recognized include The Christ Hospital Health Network in Cincinnati, OH and Allegheny General Hospital in Pittsburgh, PA.

Allegheny General Hospital
AdventHealth Orlando
Advocate Aurora St. Luke's Medical Center
Atrium Health Sanger Heart & Vascular Institute
Brigham and Women's Hospital
Cleveland Clinic Foundation-Adult
Cleveland Clinic Foundation-Pediatrics
Cleveland Clinic- Weston
Columbia Irving Medical Center
Corewell Health (formerly Spectrum Health)
Duke University Medical Center
Emory University Hospital-Adult
Emory University Hospital-CHOA-Pediatrics
Intermountain Medical Center
Le Bonheur Children's Hospital
Lahey Hospital and Medical Center
Mayo Clinic-Adult, Rochester, Scottsdale, Jacksonville
Mayo Clinic-Pediatrics
Methodist DeBakey Heart & Vascular Center
Monroe Carell Jr. Children's Hospital at Vanderbilt
Morristown Medical Center
NYU Langone Medical Center
NYU Winthrop Hospital
Oregon Health & Science University

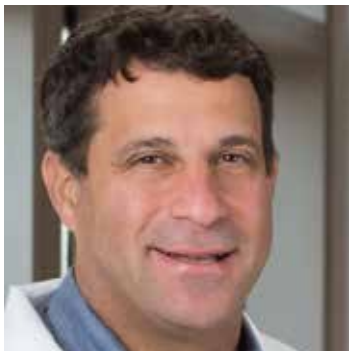
Penn State Health
Rochester Regional Health
Saint Thomas Heart
Scripps Clinic
Stanford University Medical Center
The Christ Hospital
Northwestern University
UC San Diego Health
UCLA Ronald Reagan Medical Center
UCSF Medical Center
University of Colorado
University of Iowa Hospitals and Clinics
University of Kansas Health System
University of Michigan Cardiovascular Center
University of Pennsylvania
University of Pennsylvania - CHOP
University of Texas Health Science Center at San Antonio
University of Texas Southwestern
University of Utah Health Science Center
University of Virginia Health System
UPMC Heart and Vascular Institute
Vanderbilt Medical Center
Washington University and Barnes-Jewish Hospital
Westchester Medical Center
Yale New Haven Hospital

Medical Affairs and Education

The HCMA is committed to advancing the science of HCM. In early 2022, we began using REDCap Cloud, a research database software that provides a secure server for patient record keeping. This patient registry allows HCMA to help patients stay on track with recommended care, assist with clinical trial recruitment, and more. In 2023, we began the process of applying for IRB approval of our registry. Once we obtain approval, will work with our Medical Affairs Committee to begin querying the registry for both internal and external research projects.

In partnership with PCM Scientific, HCMA supports HCM Academy, a series of free CME courses for general practitioners, family physicians, nurses, and community cardiology teams. It was created to support timely diagnosis and best-practice care for people living with HCM. Since the launch of HCM Academy in November 2021, HCM Academy has partnered with 47 international HCM expert faculty to deliver 120 CME-accredited learning activities. The HCM Academy platform has had over 425,000 page views and over 145,000 engaged learning sessions.

HCM Academy Steering Committee



Martin Maron, MD
Lahey Hospital and Medical Center



Lisa Salberg
CEO and Founder of the HCMA



Anjali Owens, MD
University of Pennsylvania



Steve R. Ommen, MD
Mayo Hypertrophic
Cardiomyopathy Clinic

Legislative

For several years, HCMA has been working to pass the Healthy Cardiac Monitoring Act (HCM Act) in every state. The HCMA Act aims to improve the ability of healthcare providers to identify children at risk for cardiac disorders. To date, we have created sample bill language, are educating policymakers, and are working with state legislators to introduce the bill.

As a step toward educating state legislators about HCM and the HCM Act, we worked in 2023 to establish a recognition day for HCM. We thank the following states for resigning the last Wednesday in February as HCM Awareness Day: Arizona, Arkansas, California, Colorado, Connecticut, Illinois, Indiana, Iowa, Kentucky, Massachusetts, Nevada, New York, Ohio, South Dakota, Texas, and Utah.

The HCMA also developed a state report card grading system and interactive map. Every state received a grade based on their legislation surrounding preparedness for cardiac emergencies and care and which components of the HCM Act the state has adopted.



In 2023, HCMA CEO and Founder Lisa Salberg traveled to Michigan to speak to legislators about the passage of the HCM Act and issues surrounding prescription drug formularies.



In 2023, the Legislative Committee is delighted with the number of states in America that recognized HCM Day with proclamations. In 2024 the work continues to expand this number, to continue engaging states to pass the HCM ACT along with the upcoming federal initiative at our country's capitol on February 15th. - Rosemary Conlon



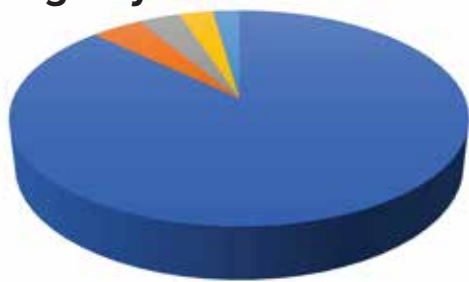
Health Equity & International

Health Equity

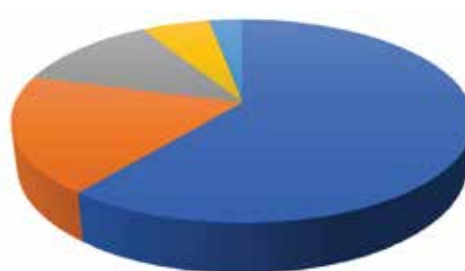
The HCMA is committed to reaching undiagnosed HCM patients in underserved communities. The Health Equity Committee aims to ensure fair and equitable representation of patients and providers of varied demographics. The committee is made up of four working groups-Pediatric, Black/African American, International-Canada, and Rural/Military. In 2023, each working group identified the top challenges for their community, which will be used to develop a series of educational whiteboard animations.

Contingent upon securing additional funding, we will also partner with Mobilizing Preachers and Communities (MPAC) and the Preventative Cardiovascular Nurses Association (PCNA) on the All Hearts Collaborative--an initiative to screen and refer parishioners at churches serving African Americans for cardiovascular diseases.

Current HCMA Patient Registry Racial Break down



U.S. Census Racial Break down



We aim for our Patient Registry to reflect the racial diversity of the U.S. population.

■ White ■ Hispanic ■ African American ■ Asian ■ More than one race



International

HCMA has a long history of collaborating with patient advocacy individuals and organizations worldwide. The goal is to identify passionate patients, clinicians, professional societies, government agencies, and industry partners to improve awareness, diagnosis, and management of HCM worldwide. As the culmination of this type of collaboration, the Hypertrophic Cardiomyopathy Swedish Society was officially launched in August 2022.

Lisa traveled to Florence for the first in-person meeting of the Global Heart Hub Cardiomyopathy Council. Passionate advocates from 22 patient organizations from many countries attended, including Australia, Brazil, Canada, Germany, Ireland, Italy, the Netherlands, Poland, Romania, Spain, Sweden, UK and the U.S. We look forward to working with these organizations in the coming year.



Conferences and Meetings

In 2023, HCMA staff spent much time on the road attending conferences and meetings to spread awareness about HCM. HCMA staff attended the HFpEF Drug Discovery and Development Summit, the American College of Cardiology Annual Scientific Session, the World Heart Federation Rare Cardiovascular Disease Forum and World Heart Summit, the Women in Government National Legislative Conference, the American Society of Echocardiology Annual Scientific Sessions, the European Society of Cardiology Congress, the World Congress of Pediatric Cardiology and Cardiac Surgery, the Global Heart Hub Cardiomyopathy Patient Council Face to Face Meeting, the Patient-Centered Outcomes Research Institute Annual Meeting, the Heart Failure Society of America Annual Scientific Meeting, the Instituto Lado a Lado Global Forum, the American Heart Association Scientific Sessions, and the Global Cardiovascular Clinical Trialists Forum.

2023 also saw the return of the HCMA Annual Patient Meeting on October 21 in Morristown, NJ. Over 200 patients, partners, and clinicians came together for an educational and inspirational event. The weekend event was preceded by a gathering of the top minds in the field for a discussion on the development of a novel endpoint for HCM clinical trials.



Please let everyone know how much I loved seeing and listening to the talks and cannot wait to do this again!! It was really nice to connect and just chat with everyone! I feel like the relaxed chatting part of it really is a LOT of what it's all about!-Karen

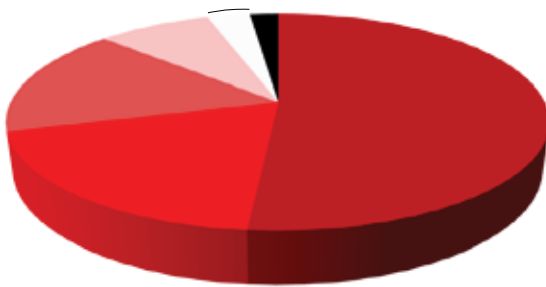


Finance

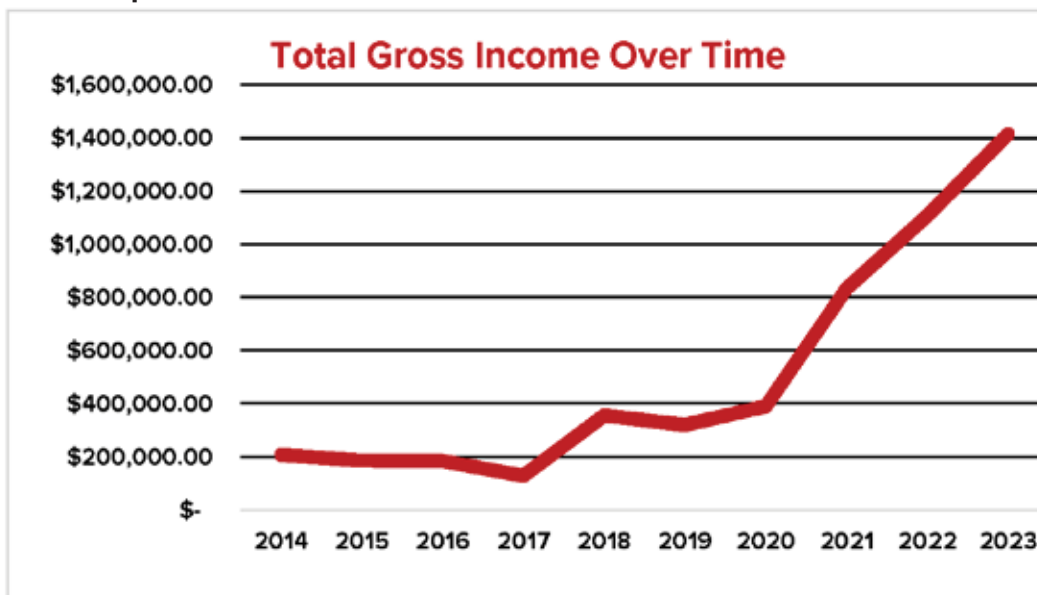
Expenses



Income



Gross Revenue: \$1,413,663
 Total Expenditures \$1,112,398
 Net Operations Revenue: \$291,265



2023: \$1,413,663
 2022: \$1,106,885
 2021: \$832,845
 2020: \$390,972
 2019: \$320,355
 2018: \$355,678
 2017: \$129,019
 2016: \$184,771
 2015: \$186,702
 2014: 208,597

Sponsors and Top Donors

Thank you to all of our big-hearted champions who helped us make the HCMA's programs possible. We would like to acknowledge the following sponsors and donors for their generous support.

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The Blackbaud Giving Fund
The Daniel Foundation
Theresa Argandona
Valerie and William Schwartz
Vanguard Charitable
Walter R Smith
Yoni and Nina Cooper

The Lori Fund

A donation to the HCMAs Lori Fund will provide micro travel grants for patients and families in need of financial support to travel to HCMA Recognized Centers of Excellence.


Since the creation of the Lori Fund in 2022 the HCMA has given out \$7,220 in travel grants.



The Lori Fund


HCMA Micro-Travel Grant
In memory of Lori Anne Flanigan-Munson

Donate Today!



Providing micro-travel grants to HCM patients traveling to a HCMA recognized Center of Excellence facility for HCM care or transplant care.


"Thank you to everyone in the office for letting me use the Lori Fund, it's truly a blessing to be able to get to appointments and not have to stress so much over finances."
- Katie, Mississippi



HCM Patient


HCMA Recognized Center of Excellence

Everyone deserves excellence in HCM care, no matter where they live. When distance and cost prohibit a patient from receiving the care they need, the **HCMA Lori Fund** is there. Since the creation of the Lori Fund we have distributed nine grants totaling \$7,220 helping families receive myectomies, transplants, and medical management otherwise out of their reach.



Hypertrophic Cardiomyopathy Association

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