Annual Report

Hypertrophic Cardiomyopathy Association

2022

HCMA Hypertrophic Cardiomyopathy Association®

Table of Contents

Founders Letters 2

Patient Engagement 3

Legislative Advocacy 4

Research 5

Partners 6

Medical Education 6

Patient Education 7

Lori Fund 8

Centers of Excellence 9-11

Finances 12

Board of Directors 13

In Gratitude 14

Unmask the Great Masquerader Ball 15

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.

Founder's Letter

Dear Friends and Supporters,
2022 was a year of tremendous growth for the HCMA. Since the HCMA's founding in 1996, we have never experienced this level of activity in all areas of the organization. In our annual report, you will find an overview of our work over the past year and our hopes for the future.

In 2022 the HCMA welcomed three new full-time staff and three new contractors to support you. We added more online discussion groups and other volunteer opportunities, including our legislative initiative, the Healthy Cardiac Monitoring Act, to improve childhood screenings to identify children and families at risk of genetic cardiac disease (Hypertrophic Cardiomyopathy, Dilated Cardiomyopathy, Arrhythmogenic Right Ventricular Cardiomyopathy, and more). In April 2022, the first-in-class drug therapy for HCM, Camzyos, was approved by the FDA for use in symptomatic hypertrophic obstructive cardiomyopathy. The HCMA Recognized Center of Excellence program continues to grow with the addition of three programs in 2022. As part of an effort to better educate community cardiologists and other healthcare providers, we are in our second year of HCM Academy, which offers CME-accredited HCM education and encourages patient care collaboration between HCMA Recognized Center of Excellence programs and community care physicians.

We would like to thank all who were so generous in their support of the HCMA. In 2022, we received almost $200,000 in donations, including over $35,000 from Facebook fundraisers that our members hosted for us. Your support helps us reach our goal of ensuring ALL patients get the opportunity for personalized support and education through our intake and navigation call process.

We accomplished so much in 2022, but more work still needs to be done to improve the lives of those living with HCM. In 2023, we will be formalizing the HCM Patient Journey database. This new system to record the patient experience will enable us, under the direction of the Medical Affairs Committee, to conduct and publish research based on YOUR experience. This will enable us to identify gaps in care and document the true patient journey. It will also allow us to collaborate with research partners and offer additional clinical trial opportunities to our members.

We hope you find our annual report format informative, however, should you have any additional questions please feel free to reach out to our amazing HCMA staff. Thank you to all of our volunteers, staff, partners, and supporters for making 2022 so wonderful.

Warm Regards,

Lisa Salberg
CEO and Founder

Patient Engagement

Patient engagement continues to be a vital component of the HCMA mission. We provide one on one support to patients through our Intake and Navigation Calls. Patients share their health histories, and we help them prepare to participate in shared decision making with their chosen health care provider. In 2022, we conducted more than 1,000 intake and navigation calls.

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 diagnoses, heart transplants, ICDs, emotional support, myectomy, and more. More than 1,000 patients registered for online discussion group meetings in 2022.

We continue to host a Facebook page with over 13,000 followers and a very active HCM Facebook group with over 9,000 members and almost 6,000 posts last year. Follow us on Facebook to stay up to date with our latest events.

Amy Lenhart

HCMA Member

> Finding the HCMA was lifesaving. My biggest emotion was fear, and so many things on the internet about HCM were outdated. It looked like maybe I wouldn't live as long, and I was afraid for myself and my family. I felt relieved at finding information through the HCMA. I had an appointment with Lisa Salberg, and her talking and listening to me and encouraging me to go to a Center of Excellence helped me emotionally, and it helped with the fear. I have the opportunity to live my life normally. There are scary things about HCM, but the biggest thing is hope, and I will be forever grateful for that.

Legislative Advocacy

In 2022, the Legislative Advocacy Committee continued its work to pass the Healthy Cardiac Monitoring Act (HCM Act) in every state. The HCM Act is proposed legislation that aims to improve the ability of healthcare providers to identify children at risk for cardiac disorders.

In the 4th quarter of 2022, our committee partnered with Bristol Myers Squibb's State Government Affairs team to begin working on another initiative to improve HCM awareness. We aim to have every state officially designate the 4th Wednesday of February each year as "Hypertrophic Cardiomyopathy Awareness Day." To date, Ohio, Texas, and Connecticut have already passed this legislation, and draft language has already been submitted to 14 additional states. We anticipate a positive response from these other states, and we will continue this effort in each state to create HCM awareness throughout the country.

Our committee members have been closely monitoring issues surrounding reproductive rights and access to quality medical care for HCM patients, Medicare Part D developments and drug prices, quality of generic drugs, and how to improve the quality of care and access to care and medicines in the age of continued consolidation of healthcare services.

Billur Dowse, MS

HCMA Board of Directors
Legislative Advocacy Committee Chair

> Our Legislative Committee members are passionate about improving the healthcare needs of all HCM patients. We will continue to work hard to improve existing policies and advance legislative decisions that positively impact the healthcare delivery systems and issues for all HCM patients.

Research

The HCMA is committed to advancing the science of HCM. In early 2022, we began using REDCap Cloud, a research database system used to design, build, and manage research studies. REDCap Cloud has a long track record for patient data collection is primarily used in acedemic programs. It has given us improved efficiency in assisting with clinical trial recruitment and provides a secure server for patient record keeping.

In 2022, we also seated our first Medical Affairs Committee. The role of the Medical Affairs Committee is to maintain scientific and clinical accuracy and rigor of the medical literature and standard of care for HCM.

We also worked with industry partners Imbria and Bristol Myers Squibb to assist with clinical trial education and recruitment for new pharmaceutical options for patients with both obstructive and non-obstructive HCM.

HCMA CEO & Founder Lisa Salberg co-authored three publications in peer-reviewed journals in 2022. The articles covered the patients' perspectives on living with HCM, the psychological symptoms and physical limitations of HCM, and the role of patient advocacy in HCM.

Borsari, W., Davis, L., Meiers, E., Salberg, L., & Barbara McDonough (2022). Living with hypertrophic cardiomyopathy: a patient's perspective. Future cardiology.

Asbeutah, A. A. A., Ingram, E., Mouksian, K., Wilbanks, D., Alexander, J., Bath, A., Salberg, L., & Jefferies, J. L. (2022). Psychological Symptoms and Physical Limitations With Hypertrophic Cardiomyopathy. The American journal of cardiology.

Salberg L. (2022). The role of patient advocacy in hypertrophic cardiomyopathy: The 25-year journey of the HCMA. Asian cardiovascular & thoracic annals.

Medical Education

HCM
Academy

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. So far, the program has been used by more than 105,000 US-based physicians and nurses delivering an average knowledge gain of +23% and competency gain of +26% amongst learners.

Partners

The HCMA developed and strengthened relationships with several key advocacy partners in 2022, including the American College of Cardiology, the American Heart Association, the Partnership to Advance Cardiovascular Health, the Preventive Cardiovascular Nurses Association, the Heart Failure Society of America, WomenHeart, Global Heart Hub, DCM Foundation, Arrhythmia Alliance, LMNA Cardiac Foundation, and the Danon Foundation.

We also expanded our relationships with industry partners Bristol Myers Squibb, Cytokinetics, Tenaya Therapeutics, Imbria, BioMarin, Pfizer, Alnylam Pharmaceuticals, Tempus, Nest Genomics, and others.

HCMA has a long history of collaborating with patient advocacy individuals and organizations worldwide with an interest in building public awareness of HCM and supporting HCM patients. We aim to develop new or expand existing patient advocacy organizations, which will be international affiliates of the HCMA. As the culmination of collaboration efforts since 2019, the Hypertrophic Cardiomyopathy Swedish Society was officially launched in September 2022.

Bristol Myers Squibb™

We would like to congratulate the HCMA on an outstanding 2022. Their continued leadership in building a strong patient community, providing helpful resources for patients, and raising awareness around the impact of HCM have had a profound influence. Much like the HCMA, at Bristol Myers Squibb we place the patient at the center of everything that we do. We were proud to work together on multiple initiatives this year, including the launch of HCM Awareness Day, and look forward to our continued work in 2023.

Patient Education

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 Recognized Centers of Excellence (COE) program brings together thought leaders in HCM patient care to discuss important topics such as novel therapies, imaging, exercise, myectomy, genetic counseling, and more. In 2022, we expanded this program to not only highlight ten of our COEs but also to include special edition webinars on pediatric HCM and the genetics of HCM. Since its inception, the Bighearted Warrior tour has reached over 50,000 people.

Lisa Salberg also hosts a weekly podcast that features educational, inspirational, and enlightening discussions with HCM stakeholders. Regularly scheduled co-hosts include Dr. Martin Maron (Lahey Hospital and Medical Center), Dr. Harry Lever (Cleveland Clinic), Dr. Steve Ommen (Mayo Clinic). In 2022, Lisa hosted over 40 podcasts which had over 15,000 impressions on Facebook and over 1,500 views on YouTube. Since the start of the podcast, Tales from the Heart has reached over 50,000 people.

The HCMA has an expansive website available for patients with a variety of educational content (4hcm.org). In 2022, we had over 140,000 new website visitors with almost 1 million engagement events and an average growth rate of 30% monthly active users.

The HCMA launched its Patient Education Committee in February 2022. The committee's initial work focused on updating and enhancing existing educational material, and especially our website. We also launched a blog feature on the website, allowing us to add short articles. On request from the HCMA office, the committee has contributed reviews and ideas for other material, including most recently a very brief introduction to diagnostic methods, to be used as part of the intake process for new patients. More recently, the committee has turned to developing longer-term guidelines for development of our work, identifying the different parts of our audience and their needs, so that we can be sure the HCMA is addressing a very broad range of people who need our services.

Gordon A Fox, PhD

HCMA Board of Directors
Patient Education Committee Chair

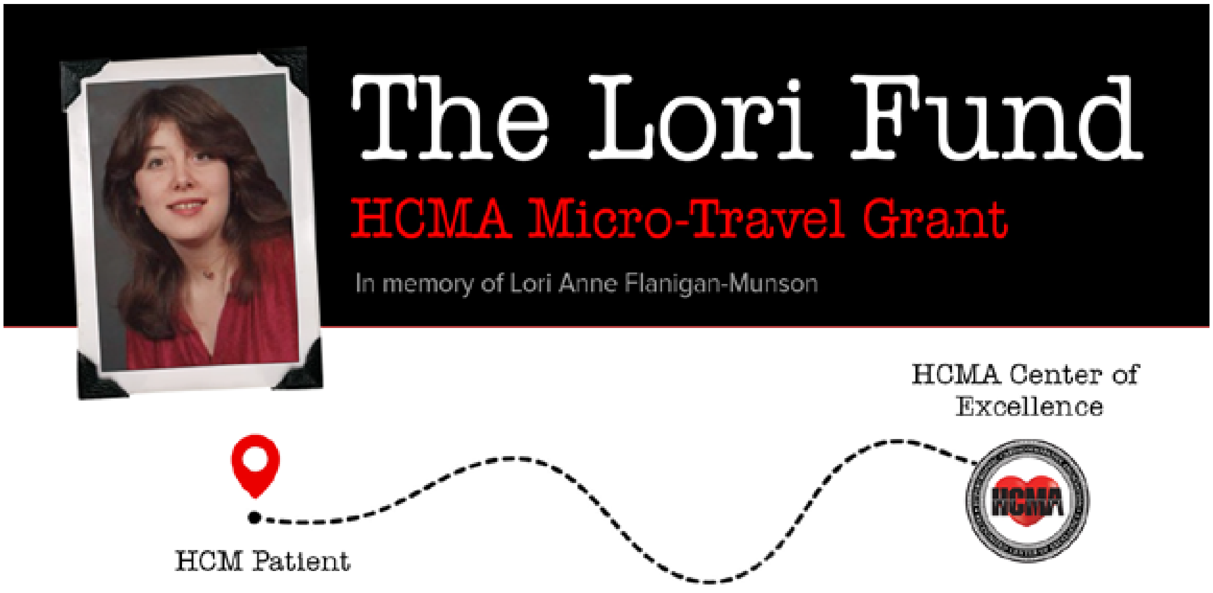
> Over the past year, the Patient Education Committee has come together as a group. It is really gratifying to see that our members feel free to make comments and to suggest new ideas, even including proposing and thinking out new initiatives. This is promising for the future: the committee doesn't depend on one or two people to think things out, but has become a true collaboration.

Lori Fund

In 2022 the HCMA launched the Lori Fund. The HCMA Lori Fund provides micro travel grants to HCM patients traveling to an HCMA Recognized Center of Excellence for care or HCM patients traveling to a facility for heart transplant care. Awards up to $600.00 are available per calendar year.

Through private donation and funds raised during the Unmask the Great Masquerader Ball the HCMA has raised enough funds to begin awarding scholarships to those in need.

This past year the HCMA raised over $14,000 to support this program.



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

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, 46 Centers have been recognized, including the addition of three new centers in 2022. The latest centers recognized include Lahey Hypertrophic Cardiomyopathy Center in Burlington, MA, Columbia University Hypertrophic Cardiomyopathy Center in New York, NY, and The University of Colorado Hypertrophic Cardiomyopathy Center in Aurora, CO.

Our 2022 Centers of Excellence were:

COE Name/Organization	Director	Co Director
AdventHealth Orlando	Dr. Marcos S. Hazday	Dr. Philip Anderson
Advocate Aurora St. Luke's Medical Center	Dr. A. Jamil Tajik	Dr. M. Fuad Jan
Atrium Health Sanger Heart & Vascular Institute	Dr. John D. Symanski	Dr. Dermot Phelan
Brigham and Women's Hospital /Cardiovascular Division	Dr. Christine Seidman	Dr. Carolyn Ho
Cleveland Clinic Foundation-Adult	Dr. Milind Desai	
Cleveland Clinic Foundation-Pediatrics	Dr. Kenneth Zahka	
Cleveland Clinic- Weston	Dr. Craig R. Asher	
Columbia University Hypertrophic Cardiomyopathy Center	Dr. Shepard Weiner	Dr. Hiroo Takayama
Duke University Medical Center	Dr. Andrew Wang	
Emory University Hospital-Adult	Dr B. Robinson Williams III	
Emory University Hospital-Sibley Heart Center-Pediatrics	Dr. Peter Fishbach	
Intermountain Medical Center	Dr. Virginia Hebl	Dr. Kia Afshar
Lahey Hypertrophic Cardiomyopathy Center	Dr. Martin Maron	Dr. Ethan Rowin
Mayo Clinic-Adult	Dr. Steve Ommen	
Mayo Clinic-Pediatrics	Dr. Michael Ackerman	
Methodist DeBakey Heart & Vascular Center	Dr. Sherif F. Nagueh	Dr. John Buergler

COE Name/Organization	Director	Co Director
Monroe Carell Jr. Children's Hospital at Vanderbilt	Dr. Justin Godown	
Morristown Medical Center- Chanin T. Mast HCM Center	Dr. Matthew W Martinez	Dr. Martin Maron
NYU Langone Medical Center	Dr. Mark V Sherrid	
NYU Winthrop Hospital	Dr. Daniele Massera	
Oregon Health & Science University	Dr. Ahmad Masri	
Penn State Health - Milton S. Hershey Medical Center Heart & Vascular Institute	Dr. Eric Popjes	
Rochester Regional Health	Dr. Bipul Baibhav	Dr. Soon Park
Saint Thomas Heart	Dr. Mark Zenker	
Scripps Clinic	Dr. Jorge Gonzalez	
Spectrum Health	Dr. David Fermin	
Stanford University Medical Center	Dr. Euan Ashley	
The Bluhm Cardiovascular Institute, Northwestern University	Dr. Lubna Choudhury	Dr. Robert O. Bonow
UC San Diego Health	Dr. Jorge Silva Enciso	Dr. Eric Adler
UCLA Ronald Reagan Medical Center	Dr. Arnold S. Baas	
UCSF Medical Center	Dr. Roselle Abraham	Dr. Theodore Abraham
The University of Colorado Hypertrophic Cardiomyopathy Center	Dr. David Raymer	Dr. Edward Gill
University of Iowa Hospitals and Clinics	Dr. Ferhaan Ahmad	
University of Kansas Health System	Dr. Loren Berenbom	
University of Maryland	Dr. Libin Wang	Dr. Vincent See
University of Michigan Cardiovascular Center	Dr. Sara Saberi	Dr. Adam Helms
University of Pennsylvania	Dr. Anjali Owens	
University of Pennsylvania - Children's Hospital of Philadelphia (CHOP)	Dr. Kimberly Lin	
University of Texas Health Science Center at San Antonio	Dr. Joseph Murgo	
University of Utah Health Science Center	Dr. Omar Wever-Pinzon	Dr. Stephen McKellar

COE Name/Organization	Director	Co Director
University of Virginia Health System	Dr. Christopher Kramer	Dr. Michael Parker Ayres
UPMC Heart and Vascular Institute	Dr. Tim Wong	
Vanderbilt Heart and Vascular Institute/Vanderbilt Medical Center	Dr. Marshall Brinkley	Dr. Lynne W. Stevenson
Washington University and Barnes-Jewish Hospital	Dr. Richard Bach	
Westchester Medical Center/ Westchester Heart & Vascular Institute	Dr. Srihari S. Naidu	
Yale New Haven Hospital	Dr. Rachel Lambert	Dr. Sounok Sen Dr. John Stendahl

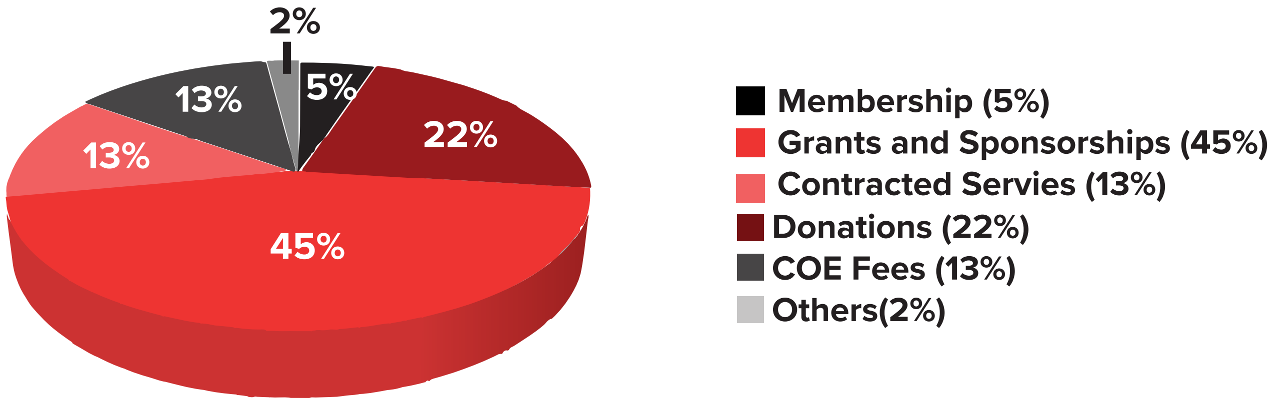
Christine Callans

HCMA Member

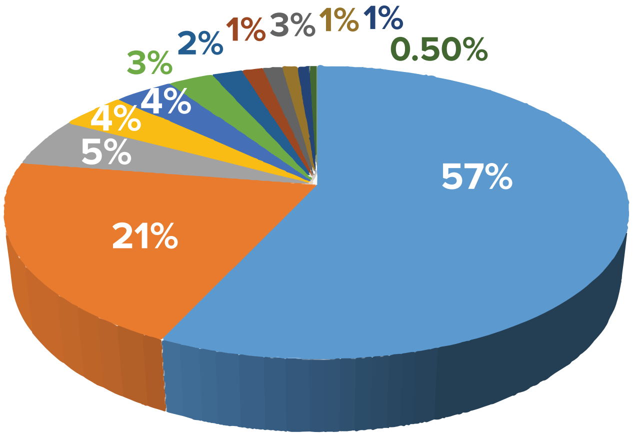
> If there's any advice I can give to newly-diagnosed patients, it's this: get hooked up with the HCMA and a center of excellence. They'll help you get the most education and best care, and that'll empower you and give you control over the disease. You'll realize you're stronger than you think.

Finances

Income

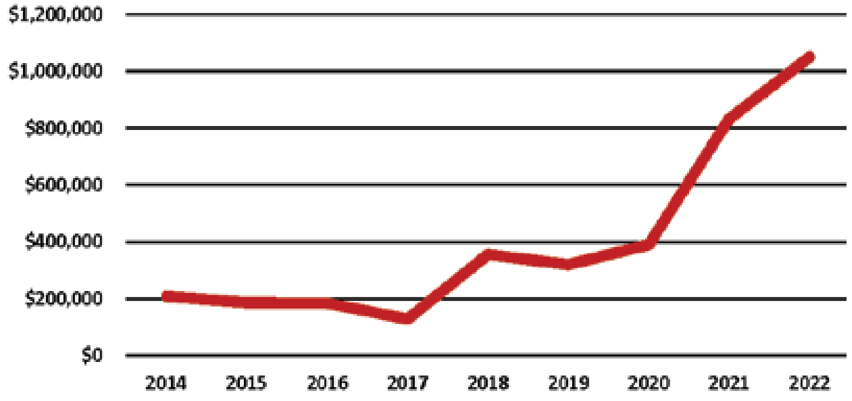


Expenses



Gross Revenue	**$1,091,860**
Total Expenditures	**$790,321.22**
NET OPERATIONS REVENUE	**$301,539.72**

Total Gross Revenue Over Time



2022: $1,091,860
2021: $832,845
2020: $390,972
2019: $320,355
2018: $355,678
2017: $129,019
2016: $184,771
2015: $186,702
2014: $208,597

Board of Directors

Amit Kalia, M.D.	Board Chair
Lisa Salberg	CEO/Founder
Adam Salberg	Secretary
Robert Lorfink	
Gordon Fox, Ph.D.	Patient Education Committee Chair
Billur Dowse	Legislative Advocacy Committee Chair
Richard Melia, Ph.D.	Finance Committee Chair
Martin Maron, M.D.	Medical Affairs Commitee Chair
Susan Blakey	
Isaac R. Rodriguiez-Chavez, Ph.D., M.S., M.H.S.	
Lynn Perry	Emeritus
Stephen Winters, M.D.	Emeritus

Amit Kalia, MD

Chairman, Board of Directors

> As the chair of the HCMA Board of Directors I’ve witnessed tremendous progress. Despite the economic landscape, the HCMA has made great strides and ensuring its financial well-being through patient and industry support. And that stability has immediately translated into increased patient outreach, greater involvement with industry to promote HCM-specific therapy and more focused legislative efforts to promote awareness and protections for HCM patients and families. As I prepare to step down after four years as the chair and resume my role as a board of directors member, I’m happy to turn over my role to the next chairperson and eager to join it even more robust and diverse board than the one I assumed years ago.

In Gratitude

$100,000+

Bristol Myers Squibb
Cytokinetics

$50,000+

Tenaya Therapeutics

$25,000+

Elizabeth McNamee Memorial Fund*
Facebook Fund Raisers
Imbria Pharmaceuticals
Susan Blakey

$10,000+

BioMarin
Board of County Commissioners
Boston Scientific
Keith Dunne
Marque Ann Barton
Melanie Schnoll Begun
Morgan Stanley Gift Fund
William H & Mattie Wattis Harris Foundation

$5,000+

Kenyon Noble Lumber Company
Marcia Robbins Wilf
TD Ameritrade Clearing

$2,500+

Benevity Community
Jim Cannistraci
Jules LeBlanc

$1,000+

Annette Sykora
Bill Keith
Bruce Bishop
Carole and Charles Sheifer
Daniel Swistel
Deanne Breedlove
Feda Morrissey
Gerard and Jill Conway
Jane Austin Lee
Jeffrey A Goelzer
John Rogers
Katja Newkirk
Kristen Leonard
Louise Weiler
Misty Everhart
NADA Foundation
Richard Hadley
Theresa Argandona
Yoni and Nina Cooper

$500+

Allen McBride
Amazon Smile
Barbara and Robert Sanderman
Christopher Barrett
Cybergrants
Daniel Adrat
David Pamenter
Eileen Boblak
Irene Ponce
Judy Jackson
Kathy Ryan
Karen Arndt
Karen Rabin
Kevin O’Connor
Kyle Wieferich
Ladonna Parris
Laef Olson
Len Levin
Les Schwab Bozeman
Lynn Saul
Main Street Community Foundation
Mark Thomas Rummler
Matthew Seigerman
Peter Wolcott
Rachel Lampert
Richard Melia
Robert Wood Johnson Foundation
Sara Montgomery
Scott Herrmeyer
Sheela Graney
Skylar Collorone
Thomas Stanis

*Special thanks to the McNamee Family for a lifetime donation total of over $500,000 over the last 20 years.

Unmask the Great Masquerader Ball

In October 2022, we held our first Unmask the Great Masquerader Ball. We gathered to recognize our four area HCMA Recognized Centers of Excellence

Morristown Medical Center
NYU Langone Health
Westchester Medical Center
New York-Presbyterian / Columbia

It was a great evening to raise funds for the HCMA Lori Fund, which provides micro travel grants to HCM patients traveling to an HCMA-recognized Center of Excellence for care or for HCM patients traveling to a facility for heart transplant care.

Join Us Next Year!

October 21st, 2023