

# 2021 ANNUAL REPORT



Hypertrophic  
Cardiomyopathy  
Association®

---

## Table of Contents

<b>Founders' Letter</b>	<b>3</b>
<b>Many programs, One mission: To improve the lives of patients living with HCM</b>	<b>4</b>
– Patient Engagement	4
– Advocacy	4
– Recruitment and Research	4
– Partners	5
– Operations	5
– Medical Education	5
– Patient Education	6
<b>Centers of Excellence</b>	<b>7</b>
<b>Finances</b>	<b>9</b>
<b>Board of Directors</b>	<b>10</b>
<b>In Gratitude</b>	<b>11</b>
<b>Ways to Give to the HCMA</b>	<b>13</b>

## Founders' Letter

Dear Friends and Supporters,

The year 2021 marked HCMA's 25<sup>th</sup> anniversary and I am so grateful for the opportunity to serve the hypertrophic cardiomyopathy community for a quarter of a century. Back in 1980 when I first received my own diagnosis of HCM, I never imagined that I would have the privilege and honor of working with the HCM community to help establish better systems to ensure patients have access to high volume quality care and support. We have built a community of extraordinary clinical partners, researchers, industry members and most importantly patients and families. We have come such a long way and we still have so far to go.

Looking back, 2021 was a very busy and very productive year. Even with the challenges of Covid-19 we were able to accomplish great things. The HCMA office took over 4,000 phone calls and hosted 10 Bighearted Warrior Tour Meetings. We added two new Center of Excellence programs. We held over 120 discussion group meetings. We also added four new staff members to the HCMA and recruited for a new clinical trial. We launched HCM Academy to educate general practitioners and community cardiologists about HCM. As well as completed partnership projects with the some amazing partner organizations.

I would like to thank all who were so generous in their support of the HCMA. In 2021, we received over \$200,000 in donations, including over \$50,000 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.

Next year holds so much for our community with new committees being formed, legislative advocacy efforts kicking off in January, and the promise of new therapies becoming available.

We hope you find our new 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 2021 so wonderful....2022, here we come!

Warm Regards,

*Lisa Salberg*

Lisa Salberg  
HCMA CEO and Founder

## Many programs, One mission: To improve the lives of patients living with HCM

### Patient Engagement

Patient Engagement continues to be a vital component of the HCMA mission. In 2021, our Intake Coordinators completed over 400 intake calls, collecting patients' health history and preparing them for a full navigation call. HCMA CEO Lisa Salberg completed over 600 navigation calls this year, guiding clients through new diagnoses, providing suggestions for genetic testing, referring patients to [Centers of Excellence](#) to meet their specific needs, and more. In January 2021, we introduced online [Patient Discussion Groups](#) to give members of our community easy access to peer support resources, and we now host 12 sessions each month. We continue to host a very active [HCM Facebook group](#) with over 8,000 members and over 400 posts per month.

### Advocacy

Patient advocacy is at the heart of the HCM. In 2021, we partnered with [The Institute for Clinical and Economic Review \(ICER\)](#) to assist in their evidence report on Mavacamten. This report aimed to assess the comparative clinical effectiveness and monetary value of Mavacamten as a first-in-class drug for the treatment of HCM.

We continued our work in legislative advocacy to create the [Healthy Cardiac Monitoring Act \(HCM Act\)](#). The bill aims to ensure the cardiovascular health needs of student-athletes and all children are met by improving the ability of healthcare providers to identify children at risk for cardiac disorders.

We began work on health equity and held our first African Americans with HCM Roundtable Discussion.

We worked collaboratively with partners to write letters to regulatory agencies on matters critical to HCM patient care and related regulatory issues.

### Recruitment and Research

The HCMA is committed to advancing the science of HCM. In 2021, we continued our work with the [LIVE-HCM study](#). We also worked with industry partners Celltrion and Imbira to assist with clinical trial recruitment for new pharmaceutical options for patients with both obstructive and non-obstructive HCM.

In 2021, HCMA CEO Lisa Salberg co-authored a poster with Abdul Aziz Asbeutah, MD and John L Jefferies, MD which was presented at the American Heart Association conference on depression and anxiety among patients living with HCM. She also co-authored an article in Future Cardiology with Wendy Borsari, Lindsay David, Eric Meiers, and Barbara McDonough entitled "Living with HCM: A Patient's Perspective."



## Partners

The HCMA developed and strengthened relationships with several key advocacy partners in 2021, including the American College of Cardiology, the American Heart Association, Illumina, the Heart Failure Society of America, WomenHeart, Sudden Arrhythmia Death Syndromes Foundation, Global Heart Hub, Heart Brothers House, Stop Afib, In a Heartbeat, Heart Valve Voice, the American Society of Echocardiography, Partnership to Advance Cardiovascular Health, National Forum for Heart Disease & Stroke Prevention, and the Preventive Cardiovascular Nurses Association.

We also expanded our relationships with industry partners Bristol Myers Squibb, the Bristol Myers Squibb Foundation, Cytokinetics, Invitae, Celltrion, and others.



HEART FAILURE SOCIETY OF AMERICA



In A Heartbeat

## Operations

2021 was an important year for the HCMA in the advancement of the organization's operations. We expanded our staffing to increase our efficiency and productivity. We hired a full-time Project Manager and Assistant Director. We also moved our Center of Excellence Director from a part-time to a full-time position based on this expanding program. We also hired a part-time Intake Coordinator and Volunteer Coordinator.

In addition, we purchased NeonCRM, a cloud-based software suite that assists nonprofit organizations with membership management, fundraising, volunteer management, events registration, custom reports, and more. We also completely redesigned our website this year. Our new expanded site provides resources for HCM patients, including information on the HCM Journey, a Center of

Excellence Directory, a blog, simple discussion group sign-ups, membership opportunities, and more. We also purchased several other software systems to simplify client scheduling, increase data security, and more.

## Medical Education

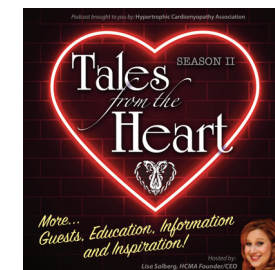
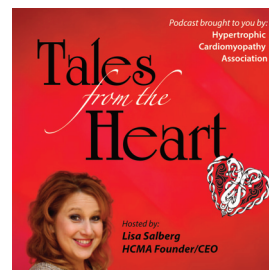


In 2021, we launched **HCM Academy**, a free digital CME initiative developed with renowned HCM specialists for physicians, aiming to improve HCM patient outcomes by enhancing knowledge and confidence surrounding efficient diagnosis and management.

In collaboration with Prime and Peerview medical education firms, the HCMA advised on content and provided the patient voice to several educational endeavors.

Finally, the HCMA partnered with various organizations, including the American Heart Association, to provide printed patient education, online content, and scientific sessions to medical providers worldwide.

## Patient Education



Patient Education continues to be core to the mission of the HCMA. In 2021, we formed a new **Patient Education Committee** which helps to develop and maintain patient education resources. This committee was integral in the redesign of the new HCMA website and our new HCM journal. CEO Lisa Salberg hosted **24 Tales from the Heart** podcasts this year, leading inspiring and informative conversations with HCM physicians, patients, and industry leaders.

We also hosted nine **Bighearted Warrior Unite** tour dates. This virtual tour of HCMA recognized Centers of Excellence program brings together thought leaders in HCM patient care and advocacy to learn together, share experiences, and work toward positive change.



## Centers of Excellence

The HCMA is committed to helping patients find the best care possible by recognizing **HCM Centers of Excellence (COEs)**—hospitals and clinics with exceptional expertise, volume of care, quality of research, patient communication, patient and medical education, and facilities.



Our 2021 Centers of Excellence:

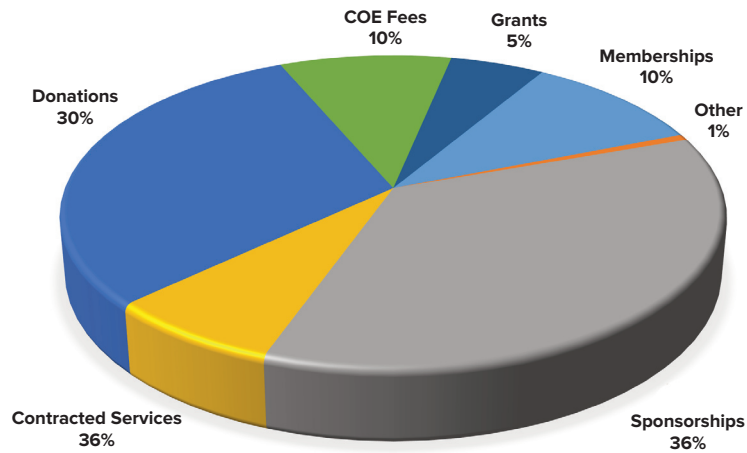
COE Name/Organization	Director	Co Director
AdventHealth Orlando	Dr. Marcos S. Hazday	Dr. Philip Anderson
Advocate Aurora St. Luke's Medical Center	Dr. A. Jamil Tajik	Dr. M. Fuad Jan
Atrium Health Sanger Heart & Vascular Institute	Dr. John D. Symanski	Dr. Dermot Phelan
Brigham and Women's Hospital / Cardiovascular 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	
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
Mayo Clinic-Adult	Dr. Steve Ommen	
Mayo Clinic-Pediatrics	Dr. Michael Ackerman	
Methodist DeBakey Heart & Vascular Center	Dr. Sherif F. Nagueh	Dr. John Buergler
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 and Vascular Institute	Dr. Eric Popjes	
Rochester Regional Health	Dr. Bipul Baibhav	Dr. Soon Park
Saint Thomas Heart	Dr. Mark Zenker	

COE Name/Organization	Director	Co Director
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
Tufts Medical Center	Dr. Martin Maron	Dr. Ethan Rowin
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
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 Texas Southwestern	Dr. Aslan Turer	Dr. Mark S. Link
University of Utah Health Science Center	Dr. Omar Wever-Pinzon	Dr. Stephen McKellar
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. Daniel L. Jacoby	



## Finances

### Revenue for 2021



#### REVENUE

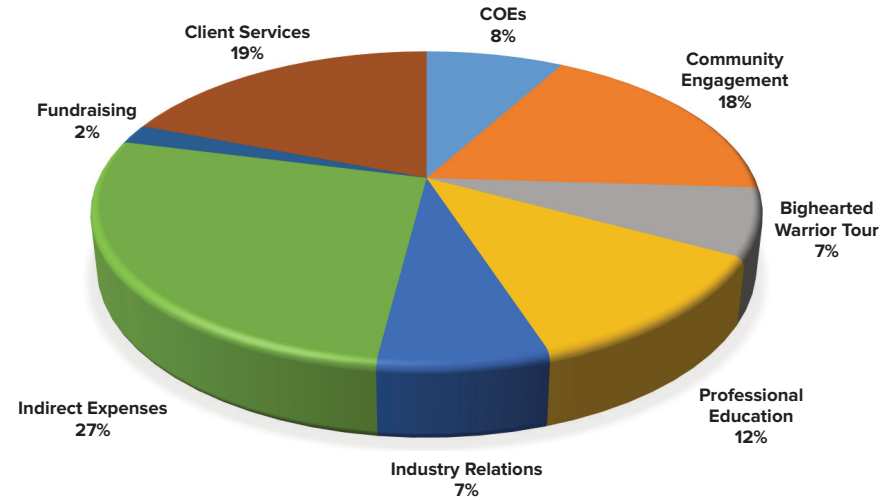
Donations	
Facebook Donations	50,273
Paypay Donations	3,183
Amazon Smile	2,100
Other	172,061
COE Fees	72,500
Grants	
Restricted	15,000
Unrestricted	24,805
Memberships	77,474
Other	
Refund/Reimbursements	1,536
Interest	289
Store Sales	2,630
Sponsorships	
Annual Sponsorships	223,000
Event Sponsorships	45,000
<b>Total Revenue</b>	<b>746,286</b>
<b>GROSS PROFIT</b>	<b>746,286</b>

\*Numbers not finalized. Officially numbers to be posted by June 1st, 2022.

#### Total revenue over time: (per 990)

2021:	746,286
2020:	390,972
2019:	320,355
2018:	355,678
2017:	129,019
2016:	184,771
2015:	186,702
2014:	208,597

### Expenses for 2021



#### EXPENSES

Marketing/Advertising	51,531
Office Expenses	62,267
Internet Systems	1,539
Office Lease	14,300
Office Utilities	1,897
Office Equipment	3,406
Contract Services	82,645
Fundraising Fees	7,502
Books and Subscriptions	21,757
Postage and Mailing	11,392
Printing and Copying	13,289
Supplies	4,455
Telecommunications	3,102
Payroll Expenses	237,756
Food	795
Insurance	6,609
Purchases	687
Reimbursements	4,523
<b>Total Expenses</b>	<b>529,452</b>
<b>NET OPERATING REVENUE</b>	<b>216,834</b>



### Facebook Group

**99** countries represented  
**1,722** new 2021 members  
**8,068** total members  
**5,595** posts  
**109,914** comments  
**250,231** reactions



### Other Social Media Numbers

**12,700** Facebook page followers  
**2,350** LinkedIn Group members  
**931** Youtube channel subscribers  
**3,550** views on our 2021 Youtube videos



### Centers of Excellence

**43** Centers of Excellence  
**215** HCMA scholarship memberships sent to our COEs for distribution  
**850** "My HCM Journey Journals" distributed to COEs

### Patient Engagement

**9** Big Hearted Warrior Tour Dates  
**24** Tales from the Heat Podcasts  
**168** Online Patient Discussion Groups  
**400+** new client intake calls  
**600+** new client navigation calls  
**1,206** event registrations

## Ways to Give to the HCMA



### Amazon Smile:

Amazon Smile is a website operated by Amazon that features the same products at the same prices as the standard Amazon site. The only difference is, when you shop using the Amazon Smile site, the Amazon Smile Foundation will donate 0.5% of the cost of all eligible products to your chosen charity.



### Facebook Fundraisers:

If you are a Facebook user, you can host a fundraiser in honor of your birthday, as a memorial of someone lost to HCM, or just to support the HCMA. With just a few clicks you can post a Fundraiser which encourages your friends and family to donate to the HCMA. We brought in over \$60,000 from Facebook fundraisers in 2021.



### Gifts of Securities:

Be Bighearted, increase the size of your gift to the HCMA and avoid capital gains tax by transferring your securities. In addition to avoiding capital gains tax, you would still enjoy an income tax deduction in the amount of the fair market value of the stock donated, up to 20% of your adjusted gross income.



### Retirement Plan Assets:

A retirement plan can be a tax-efficient and simple way to include the HCMA in your estate plan. Because charities do not pay income taxes on the donations they receive, distributions to charities will avoid being taxed as income.



### Will or Trust:

Remembering the HCMA in your will or bequest is a meaningful way to help our efforts in early diagnosis, shared decision making, and patient education.



### Life Insurance:

If you have a life insurance policy that you no longer need because of a change in your life circumstances, you can give a paid-up policy to the HCMA.

## In Gratitude

<b>\$50,000+</b>	Bristol Myers Squibb Facebook collective fundraising efforts MyoKarida
<b>\$10,000+</b>	Elizabeth McNamee Memorial Fund* Invitae Marque Ann Barton Morgan Stanley Gift Fund Rob Lorfink SDK Sports (The McLaughlin Family) Susan Blakey William H & Mattie Wattis Harris Foundation
<b>\$5,000+</b>	Alison Elizabeth Conklin Fundraising Event Melanie Schnoll Begun Schwab Charitable
<b>\$1,000+</b>	Amazon Smile** Bank of America Charitable Gift Fund Bill Keith Carrie and Jika Evans and Gqiba-Knight Chris Cummins Cohen Family Foundation Erik Clausen Erin Beck Maver's Facebook Fundraiser Feda Morrissey Jamie & Justine Bottcher Jim & Gina Penn Judy Jackson Karen and Tony Ferraro Katja Newkirk Kristie Marsden's Facebook Fundraiser Lisa Salberg's Facebook Fundraiser Louie & Dena Loucks Marcia Robbins Wilf Michelle Young Mike and Diane Evans Molly Joseph's Facebook Fundraiser MUNS Booster Club Niels Fache Sass Somekh Schwab Charitable Scott Westgate's Facebook Fundraiser Steve Young Sunrise Homes Suresh Kondamareddy T. Rowe Price Program for Charitable Giving Tyler Severson Yoni Cooper

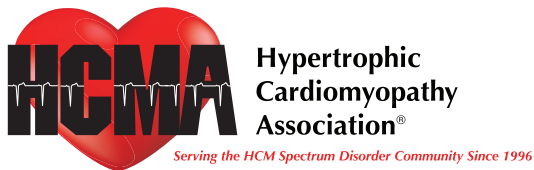
\*Special thanks to the McNamee Family for a lifetime donation total of over \$500,000 over the last 20 years.

\*\*Amazon Smile is a website operated by Amazon. It features the same products at the same prices as the standard Amazon site. The only difference is, when you shop using the Amazon Smile site, the Amazon Smile Foundation will donate 0.5% of the cost of all eligible products to your chosen charity.

## Board of Directors

Amit Kalia, M.D.	Board Chair
Susan Blakey	
Billur Dowse	Legislative Advocacy Committee Chair
Gordon Fox, Ph.D.	Patient Education Committee Chair
Carlton Hornung, Ph.D., M.P.H.	Medical Affairs Committee Co-Chair
Robert Lorfink	
Martin Maron, M.D.	
Richard Melia, Ph.D.	Finance Committee Chair
Lynn Perry	
Isaac R. Rodriguez-Chavez, Ph.D., M.S., M.H.S.	
Adam Salberg	
Lisa Salberg	Vice Chair, HCMA CEO and Founder
Stephen Winters, M.D.	





18 East Main St. Suite 202, Denville, NJ 07834  
P: 973-983-7429 | F: 973-983-7870 | [4hcm.org](http://4hcm.org)