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Founders’ Letter

Dear Friends and Supporters,

The year 2021 marked HCMA’s 25th 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
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.”
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.

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 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 Patient Education Committee 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.

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

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## 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:

<table>
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<tr>
<th>COE Name/Organization</th>
<th>Director</th>
<th>Co Director</th>
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<tbody>
<tr>
<td>AdventHealth Orlando</td>
<td>Dr. Marcos S. Hazday</td>
<td>Dr. Philip Anderson</td>
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<tr>
<td>Advocate Aurora St. Luke’s Medical Center</td>
<td>Dr. A. Jamil Tajik</td>
<td>Dr. M. Fuad Jan</td>
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<td>Atrium Health Sanger Heart &amp; Vascular Institute</td>
<td>Dr. John D. Symanski</td>
<td>Dr. Dermot Phelan</td>
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<tr>
<td>Brigham and Women’s Hospital / Cardiovascular Division</td>
<td>Dr. Christine Seidman</td>
<td>Dr. Carolyn Ho</td>
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<tr>
<td>Cleveland Clinic Foundation-Adult</td>
<td>Dr. Milind Desai</td>
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<tr>
<td>Cleveland Clinic Foundation-Pediatrics</td>
<td>Dr. Kenneth Zahka</td>
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<tr>
<td>Cleveland Clinic-Weston</td>
<td>Dr. Craig R. Asher</td>
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<tr>
<td>Emory University Hospital-Adult</td>
<td>Dr. B. Robinson Williams III</td>
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<tr>
<td>Emory University Hospital-Sibley</td>
<td>Dr. Peter Fishbach</td>
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<tr>
<td>Emory University Hospital-Pediatric Cardiology Center</td>
<td>Dr. Virginia Hebl</td>
<td>Dr. Kia Afshar</td>
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<tr>
<td>Mayo Clinic-Adult</td>
<td>Dr. Steve Ommen</td>
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<tr>
<td>Mayo Clinic-Pediatrics</td>
<td>Dr. Michael Ackerman</td>
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<tr>
<td>Methodist DeBakey Heart &amp; Vascular Center</td>
<td>Dr. Sherif F. Nagueh</td>
<td>Dr. John Buergler</td>
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<tr>
<td>Monroe Carell Jr. Children’s Hospital at Vanderbilt</td>
<td>Dr. Justin Godown</td>
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<tr>
<td>Morristown Medical Center-Chanin T. Mast HCM Center</td>
<td>Dr. Matthew W Martinez</td>
<td>Dr. Martin Maron</td>
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<tr>
<td>NYU Langone Medical Center</td>
<td>Dr. Mark V Sherrid</td>
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<tr>
<td>NYU Winthrop Hospital</td>
<td>Dr. Daniele Massera</td>
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<tr>
<td>Oregon Health &amp; Science University</td>
<td>Dr. Ahmad Masri</td>
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<tr>
<td>Penn State Health - Milton S. Hershey Medical Center Heart and Vascular Institute</td>
<td>Dr. Eric Popjes</td>
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<tr>
<td>Rochester Regional Health</td>
<td>Dr. Bipul Baibhav</td>
<td>Dr. Soon Park</td>
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<tr>
<td>Saint Thomas Heart</td>
<td>Dr. Mark Zenker</td>
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<td>Scripps Clinic</td>
<td>Dr. Jorge Gonzalez</td>
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<tr>
<td>Spectrum Health</td>
<td>Dr. David Fermin</td>
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<tr>
<td>Stanford University Medical Center</td>
<td>Dr. Euan Ashley</td>
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<tr>
<td>The Bluhm Cardiovascular Institute, Northwestern University</td>
<td>Dr. Lubna Choudhury</td>
<td>Dr. Robert O. Bonow</td>
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<tr>
<td>Tufts Medical Center</td>
<td>Dr. Martin Maron</td>
<td>Dr. Ethan Rowin</td>
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<tr>
<td>UC San Diego Health</td>
<td>Dr. Jorge Silva Enciso</td>
<td>Dr. Eric Adler</td>
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<tr>
<td>UCLA Ronald Reagan Medical Center</td>
<td>Dr. Arnold S. Baas</td>
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<tr>
<td>UCSF Medical Center</td>
<td>Dr. Roselle Abraham</td>
<td>Dr. Theodore Abraham</td>
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<tr>
<td>University of Iowa Hospitals and Clinics</td>
<td>Dr. Ferhaan Ahmad</td>
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<tr>
<td>University of Kansas Health System</td>
<td>Dr. Loren Berenborn</td>
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<tr>
<td>University of Maryland</td>
<td>Dr. Libin Wang</td>
<td>Dr. Vincent See</td>
</tr>
<tr>
<td>University of Michigan Cardiovascular Center</td>
<td>Dr. Adam Helms</td>
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<tr>
<td>University of Pennsylvania</td>
<td>Dr. Anjali Owens</td>
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<tr>
<td>University of Pennsylvania - Children’s Hospital of Philadelphia (CHOP)</td>
<td>Dr. Kimberly Lin</td>
<td></td>
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<tr>
<td>University of Texas Health Science Center at San Antonio</td>
<td>Dr. Joseph Murgo</td>
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<tr>
<td>University of Texas Southwestern</td>
<td>Dr. Aslan Turer</td>
<td>Dr. Mark S. Link</td>
</tr>
<tr>
<td>University of Utah Health Science Center</td>
<td>Dr. Omar Wever-Pinzon</td>
<td>Dr. Stephen McKellar</td>
</tr>
<tr>
<td>University of Virginia Health System</td>
<td>Dr. Christopher Kramer</td>
<td>Dr. Michael Parker Ayres</td>
</tr>
<tr>
<td>UPMC Heart and Vascular Institute</td>
<td>Dr. Tim Wong</td>
<td></td>
</tr>
<tr>
<td>Vanderbilt Heart and Vascular Institute/Vanderbilt Medical Center</td>
<td>Dr. Marshall Brinkley</td>
<td>Dr. Lynne W. Stevenson</td>
</tr>
<tr>
<td>Washington University and Barnes-Jewish Hospital</td>
<td>Dr. Richard Bach</td>
<td></td>
</tr>
<tr>
<td>Westchester Medical Center/ Westchester Heart &amp; Vascular Institute</td>
<td>Dr. Srinath N. Naidu</td>
<td></td>
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<tr>
<td>Yale New Haven Hospital</td>
<td>Dr. Daniel L. Jacoby</td>
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**Finances**

### Revenue for 2021

**COEs Fees**: 10%

**Grants**: 5%

**Memberships**: 10%

**Other**: 1%

**Donations**: 30%

**Contracted Services**: 36%

**Sponsorships**: 36%

### 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
- **Total Revenue**: $746,286

**GROSS PROFIT**: $746,286

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

### Expenses for 2021

**Client Services**: 19%

**COEs**: 8%

**Community Engagement**: 18%

**Fundraising**: 2%

**Bighearted Warrior Tour**: 7%

**Indirect Expenses**: 27%

**Industry Relations**: 7%

**Professional Education**: 12%

### 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**: $13,289
- **Printing and Copying**: $11,392
- **Supplies**: $687
- **Telecommunications**: $4,455
- **Payroll Expenses**: $237,756
- **Food**: $795
- **Insurance**: $6,609
- **Purchases**: $687
- **Reimbursements**: $4,523
- **Total Expenses**: $529,452

**NET OPERATING REVENUE**: $216,834
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

$50,000+
- Bristol Myers Squibb
- Facebook collective fundraising efforts
- MyoKarida

$10,000+
- Elizabeth McNamee Memorial Fund*
- Invitae
- Marque Ann Barton
- Morgan Stanley Gift Fund
- Rob Lorink
- SDK Sports (The McLaughlin Family)
- Susan Blakey
- William H & Mattie Wattis Harris Foundation

$5,000+
- Alison Elizabeth Conklin Fundraising Event
- Melanie Schnoll Begun
- Schwab Charitable

$1,000+
- 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 Mauer’s Facebook Fundraiser
- Feda Morrissey
- Jamie & Justine Böttcher
- 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.

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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 Lorink ................................
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. .................