



**DCM Foundation**  
Hope for People with Dilated Cardiomyopathy



Genetic Cardiomyopathy  
Awareness Consortium



The DCM Foundation's mission is to provide HOPE and support to DCM Patients and Families with Dilated Cardiomyopathy through education, research and advocacy. This mission is being executed through three foundational pillars:

1. Information and Education
2. Patient and Family Support
3. Increased Awareness of the NEED for Genetic Testing

## 2025 *Highlights and Impact*

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**2025 was a year of growth in serving DCM and Genetic Cardiomyopathy Patients and Families and helping to expedite potential life-saving therapies.**

We saw significant growth in our outreach efforts through social media, email, webinars, and content development. We reached more cardiomyopathy patients through communication through our Gene Specific Facebook Groups and partner groups. We developed important relationships with other organizations like HeartCharged to reach new audiences.

2025 was also a year focused on developing and sharing more specific cardiomyopathy content with patients and the medical community. Through the development of gene specific expert videos, informational webinars on important topics including research and therapies, and working in tandem with private industry to provide free genetic testing, we made significant strides in helping patients with cardiomyopathy in 2025.

In 2026, we will continue to develop relevant content and provide support for patients, share important research, inform patients about clinical trials and new therapies, and increase our outreach to the medical community.



## Webinars

In 2025, DCMF/GCAC hosted **eight webinars** on varying topics important to cardiomyopathy patients, their families, and medical professionals. These hour-long presentations feature industry experts sharing information on research, therapies, support opportunities, patient stories, and other issues critical to the cardiomyopathy patient community.

Registration for these webinars ranged from **200 to 550 people** and recordings of these webinars are available on our website and can be translated into over 100 languages. **Over 2,200 people registered** for our webinars in 2025.

In addition, we also hosted our **first ever webinar to the cardiology medical community** in October: Transforming Cardiomyopathy Care: The Critical Role of Genetics and Patient Support. We plan to host additional webinars specific to the medical community in 2026.

## Social Media

In 2025, social media continued to expand the reach and visibility of both organizations, connecting more patients, families, and healthcare professionals to trusted education and support. GCAC's Instagram community grew from **241 to 390 followers** (+62%), while DCM's Instagram increased from **1,000 to 1,200** followers (+20%). Facebook audiences saw even stronger gains, with GCAC expanding from **216 to 1,100 page likes** and DCM growing from **2,000 to 2,200**, reflecting steady community momentum across both brands. Over the course of the year, Meta platforms delivered substantial awareness, generating over **570K views** for GCAC and **2.7M views** for DCM, amplifying patient stories, research updates, webinars, and testing resources to millions.

On LinkedIn, both organizations continued to strengthen professional reach and credibility, growing followers and generating thousands of impressions and clicks that connected with clinicians, researchers, and industry partners.

## Financial Overview

### DCM Foundation 2025 Financials

Cash Position as of 12/31/24	\$326,089
Donations/Income	\$653,366
Patient Partner Group Payouts	\$70,250
Net Donations/Income	\$583,116
Expenses	\$484,472
Excess Income over Expenses	\$98,644
Cash Position as of 12/31/25	\$424,733

## Facebook Groups

DCMF/GCAC regularly share news, research, upcoming webinars, and important information to 18 Gene Specific Facebook Groups. Of these 18 groups, we are the main or co-administrator for 16 of these groups. 5 new groups were added in 2025 (PLN, PRKAG2, Genetic Cardiomyopathy, Gene Elusive, TNNC1, DES). These groups represent 3,525 patients world-wide. In 2025, 948 new patients joined one of these Facebook groups.

Added 948 new patients in one year.  
**a 37% increase**

## Email Communications

Email continued to be one of our most effective tools for direct, meaningful communication with our community. Over the past year, the Genetic Cardiomyopathy Awareness Consortium marketing list grew by approximately 850 subscribers and the Dilated Cardiomyopathy Foundation list added about 150, with webinar registrations serving as a key driver of new sign-ups.

Engagement remains strong compared to nonprofit industry benchmarks: GCAC emails achieved a **25.94% average open rate and 5.9% click-through rate**, exceeding typical nonprofit click rates and performing near or above sector averages for opens, while the DCM Foundation's **18.27% open rate and 3.4% click-through rate** aligns with standard nonprofit performance. These results reflect an engaged audience that actively seeks our educational updates, research opportunities, and support resources.

# New Programs Launched and Impact

## Genetic Testing

DCMF/GCAC was instrumental in the development of **free genetic testing options for cardiomyopathy patients and families** and **over 700 patients and families ordered the free tests**. At the core of developing new therapies and eventually a cure, is getting more cardiomyopathy patients genetically tested and for previously tested patients to get retested.



We worked closely with Everygene, a new and free genetic testing service, to inform cardiomyopathy patients of the need, value, and availability of genetic testing. We developed a series of three videos focused on each step of the process to help patients understand the process.

♥ **Video 1 - How Genetic Testing Can Improve Your Care**

♥ **Video 2 - When to Get Genetically Retested**

♥ **Video 3 - Understanding Genetic Testing Results**



## Expert Videos

In 2025, we developed a series of expert videos on gene specific content to help provide more specific information to patients and their families. In total, we produced 13 videos that are available on the GCAC website.

These include overview videos on cardiomyopathy and genetic testing and 11 gene specific videos (Gene Elusive, BAG3, Danon, DSP, FLNC, LMNA, MYBC3, MYH7, PKP2, PLN, TITIN, TNNT2, and YPM1).

Additional expert videos will be developed in 2026.



## Medical Professionals

In 2025, DCMF/GCAC began developing a strategic outreach campaign to the medical community. Specifically to cardiologists, nurse practitioners, and nurses. We believe that educating this audience on genetics in cardiomyopathy is essential in getting more patients genetically tested. This outreach plan will kick-off in earnest in 2026.

### The plan includes:

- ♥ The development of informational pieces that can be shared with patients.
- ♥ Webinars with specific content to medical professionals.
- ♥ Emails to our list of 18,000 US cardiomyopathy professionals.
- ♥ The development of a specific website landing page for medical professionals to make all content and information easy to find in one location.
- ♥ Press releases to medical publications.



## Helping Us Create a Bigger Impact in 2026 & Beyond

On October 23, 2025 the DCM Foundation held a fundraiser in Oakland, California graciously hosted by Ryan & Rebecca Graciano. The evening was an opportunity to share the mission and success of the foundation and to outline the vision for the future. Over 75 people attended the event and over \$100,000 was raised for the foundation.



**\$100,000+**  
Fundraising Goal Achieved



### Speakers during the event included:

- ♥ **Rebecca Graciano** DCM patient and DCMF Board member
- ♥ **Bo Nemelka** DCM patient and DCMF Board member
- ♥ **Dr. Ray Hershberger** DCMF Board member
- ♥ **Ana Morales** Certified Genetic Counselor
- ♥ **Greg Ruf** DCM patient and Executive Director of the DCM Foundation

## Partner Organizations

### Patient Groups

We work closely with other patient support groups to reach as many patients as possible with important information and resources.



LMNA Cardiac Diseases Network



The Mended Hearts, Inc.



DCM Foundation  
Hope for People with Dilated Cardiomyopathy



WOMENHEART  
THE NATIONAL COALITION FOR WOMEN WITH HEART DISEASE



Sudden Cardiac Arrest Foundation  
RAISING AWARENESS SAVING LIVES

### Industry Partners

GCAC supports the research efforts of industry partners through our communication channels to our patients informing them of upcoming research and clinical trials.

