

# Women Leaders Elevating Patient Voices in Advocacy: Harnessing Passion and Purpose in the State Capitals and Beyond

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*#AccessToHealthCare*



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Presented by: Lisa Salberg CEO and Founder



**Hypertrophic  
Cardiomyopathy  
Association**

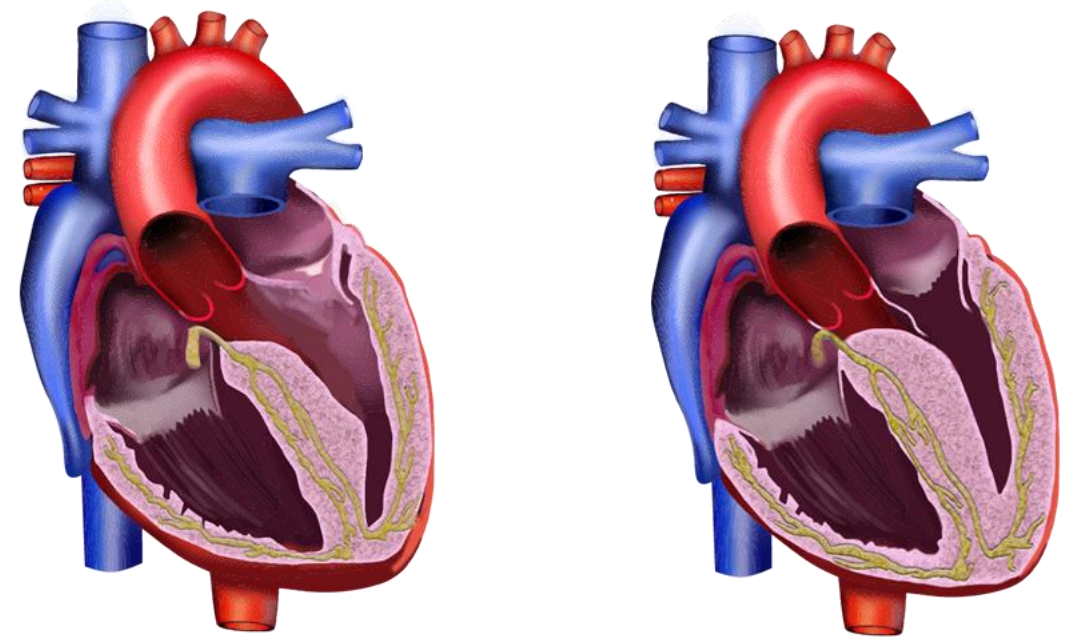
*Serving the HCM Spectrum Disorder Community Since 1996*

# The Hypertrophic Cardiomyopathy Association

Is a 501c3 providing support, advocacy, and education to patients, families, the medical community, and the public about hypertrophic cardiomyopathy while supporting research and fostering the development of treatments.

## What is HCM?

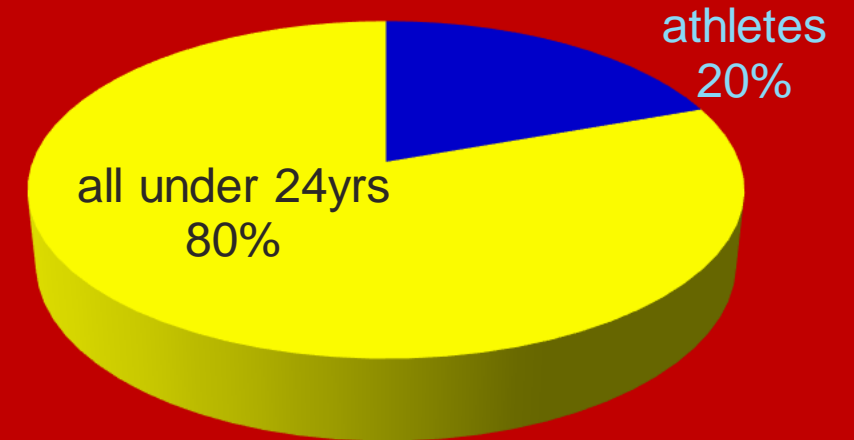
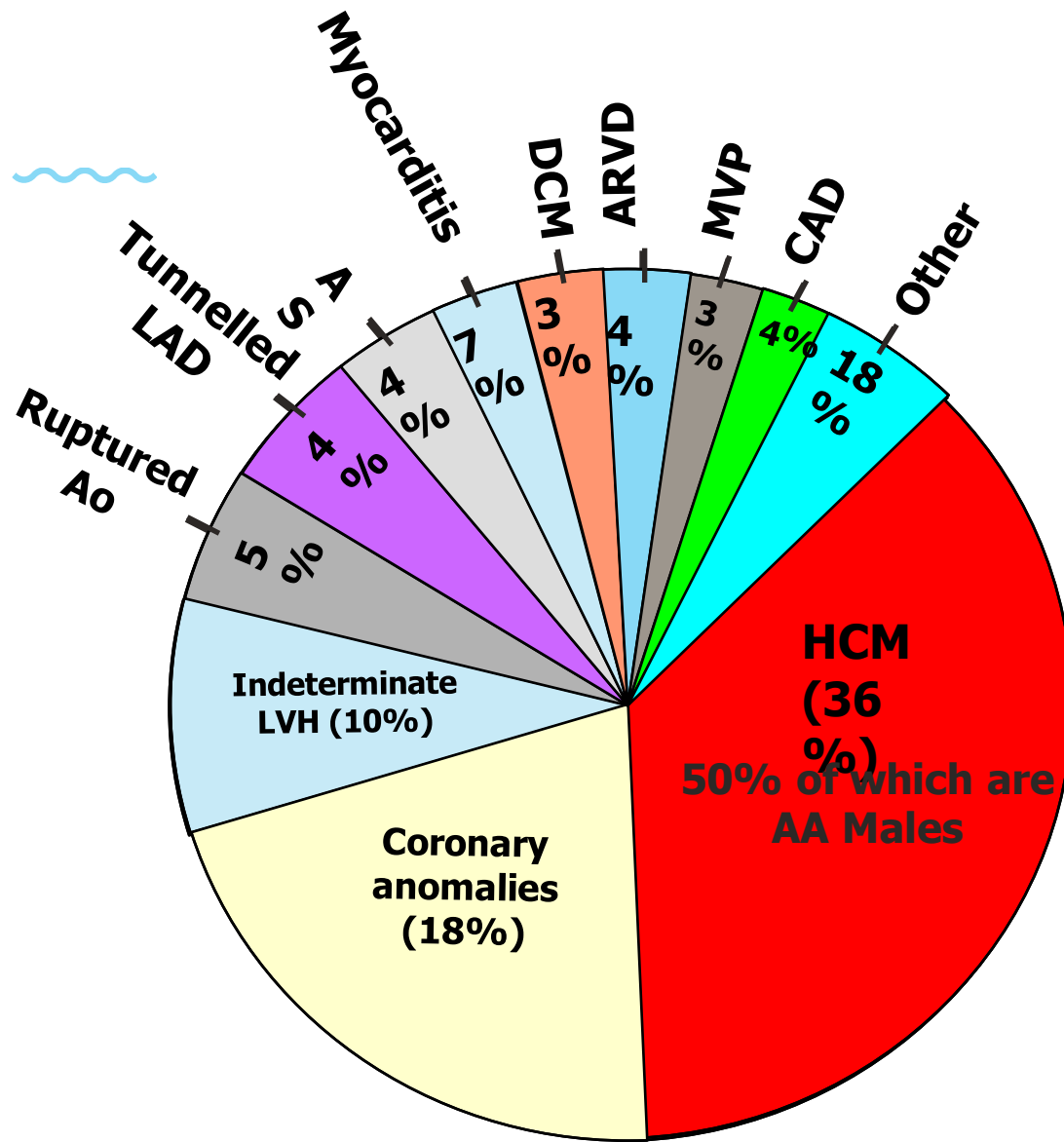
Hypertrophic cardiomyopathy (HCM) is a common genetic disorder that affects people regardless of gender, ethnicity, age or geographic location. HCM causes the heart to be thick, stiff and fails to pump blood properly. It can lead to shortness of breath, palpitations, arrhythmias, heart failure, and sudden cardiac arrest.



**Prevalence Between:**  
**1 and 200 and 1 and 500**  
663,800-1.6m potential HCM Patients

# You may have heard about Cardiac Arrest in Young Athletes, but, do you know the cause?

We know, thanks to the SCD in Athletes Registry, that approximately 75 young Athletes die each year and most will die from HCM however...

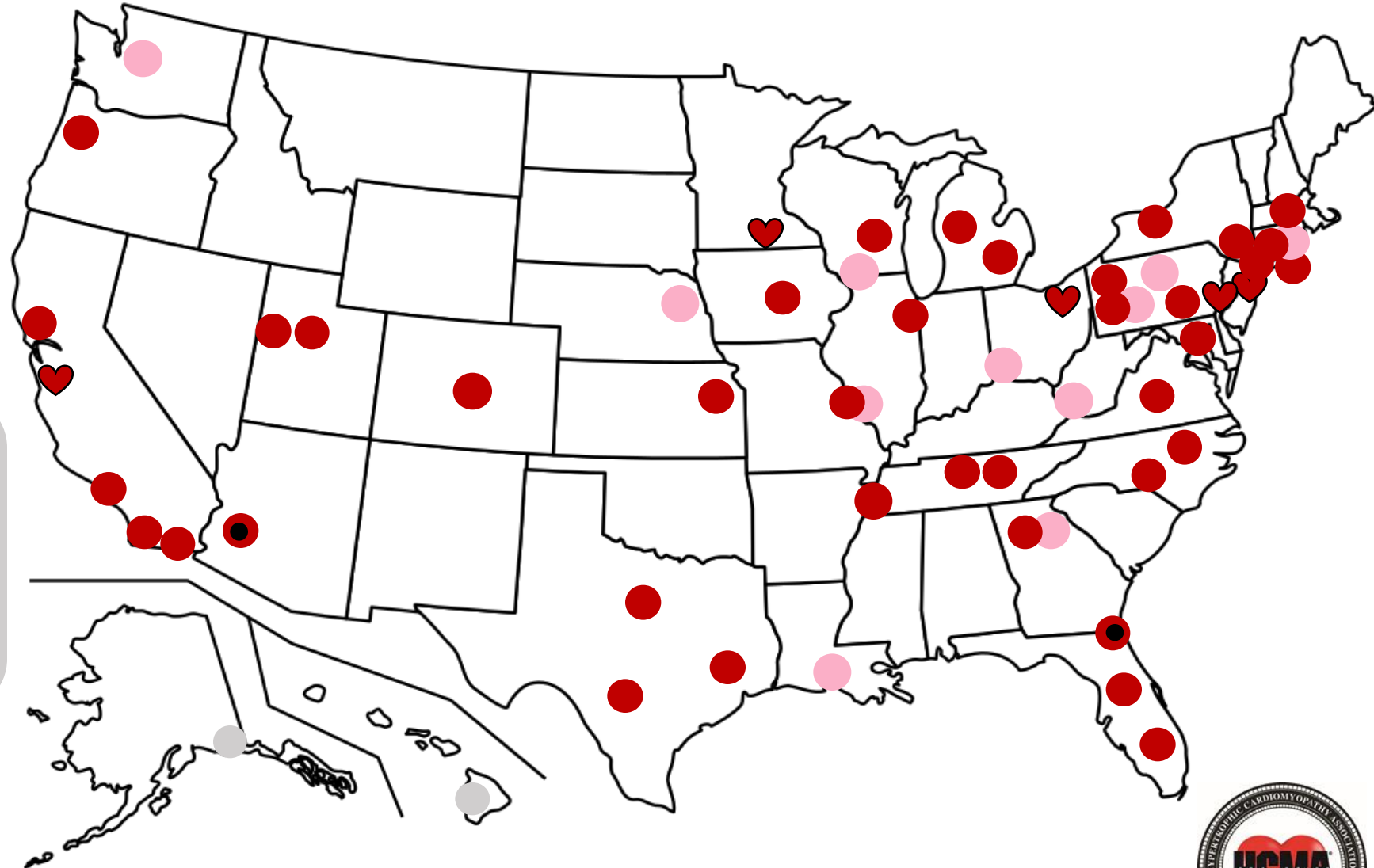


# HCMA Recognized Centers of Excellence



- ♥ COE over 3000+ pts
- COE
- Program under evaluation
- Program pending evaluation

**Today an estimated  
55,000+ are  
managed each year  
at HCMA recognized  
COE's!**





National  
**Eczema**  
Association

[NationalEczema.org/Advocacy](https://NationalEczema.org/Advocacy)

# Women Leaders Elevating Patient Voices in Advocacy



Michele Guadalupe

June 9, 2023



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# Overview of Eczema and NEA







# Eczema – Common, Chronic, and Serious

## Leading contributor to skin-related disability globally

Ranks 15th among all non-fatal diseases

## Affects over 31 million Americans of all ages and races

9.6 million children (<18 years)

33% with moderate to severe disease

16.5 million adults

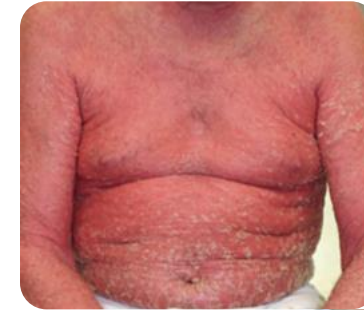
40% with moderate to severe disease

## Typical onset at <5 years of age

Persistence can occur childhood to adulthood

Can occur in adulthood for the first time

Second peak of prevalence after age 60





# Atopic Dermatitis Affects More Than Skin



## Signs/Symptoms Co-occurring Conditions

- Persistent itch
- Oozing and skin color changes
- Atopic and non-atopic conditions
- Frequent skin infections



## Psychological Distress



- Anxiety
- Depression
- Negative impact on quality of life for both patient and caregivers

## Sleep Disruption



- 90% - at least 1 night of disrupted sleep/week
- 50% - at least 5 nights of disrupted sleep per week
- Contributes to poorer work and school performance

## Burden of Care

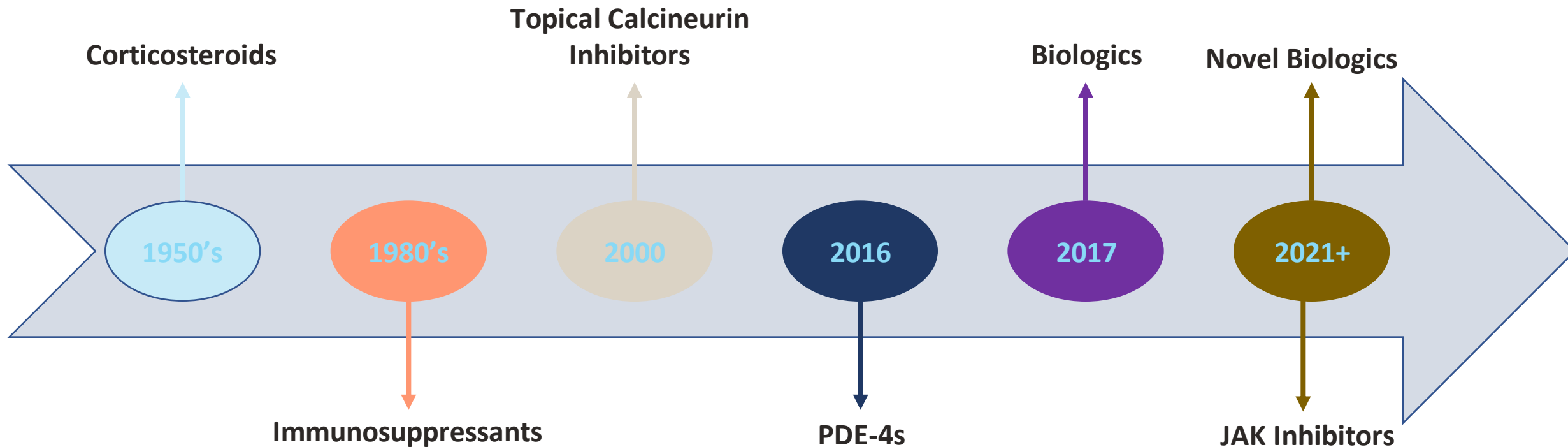
- Time spent managing condition
- Use of OTC and Rx
- Managing side effects
- Barriers limiting access
- Cost of care



# A New Era of AD Treatment and Care



- Pathophysiology is complex, yet new insights have led to several recent FDA-approved agents (for adults and children) and many more in drug discovery
- Additional treatments are needed as treatment response is variable, including non-responders



# National Eczema Association (NEA)



The sole patient advocacy organization serving **exclusively people with eczema** in the U.S.

## Vision

A world without eczema

## Mission

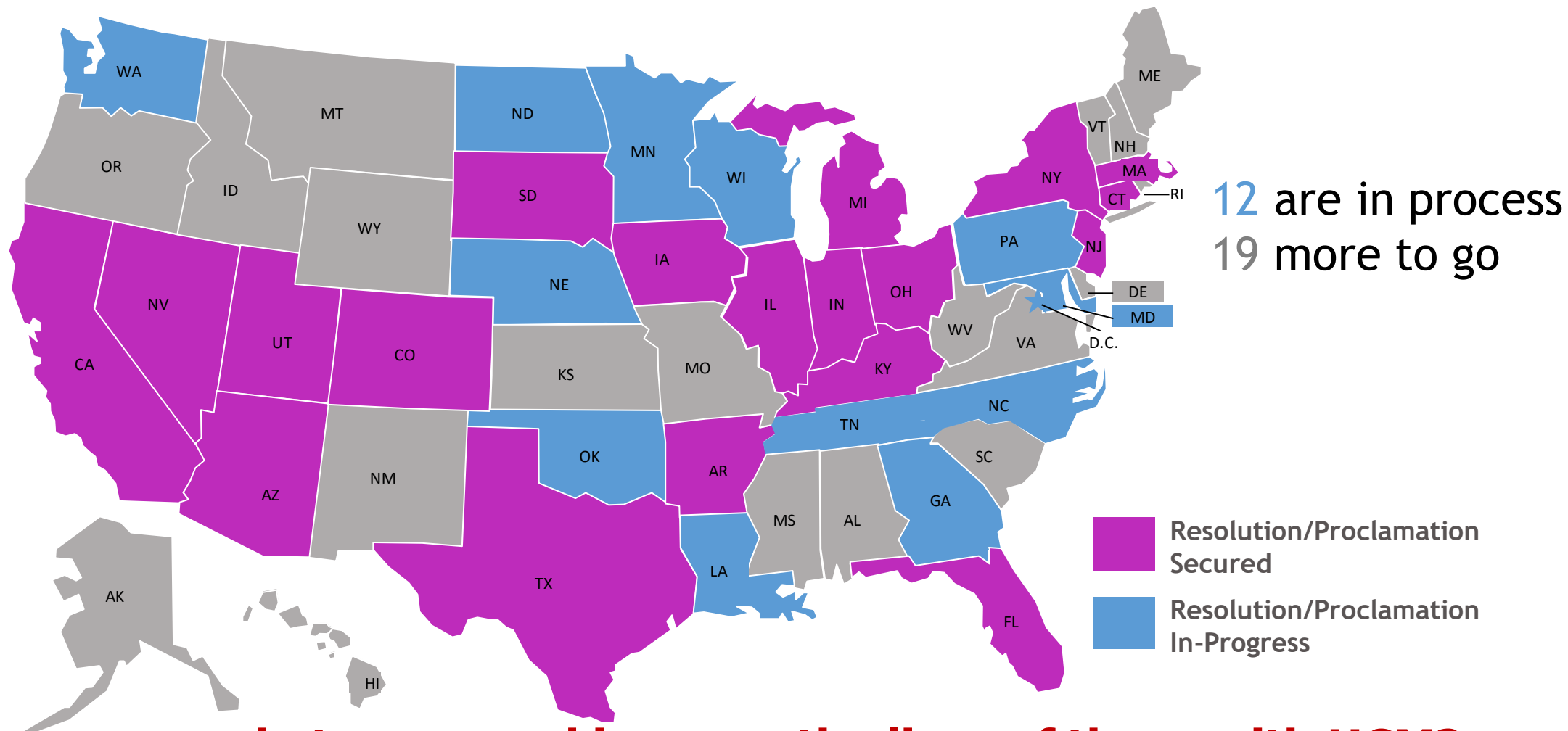
NEA is the driving force for the eczema **community** that is fueled by **knowledge**, strengthened through **collective action** and propelled by the promise for a better future.



# Pillars of Programmatic Focus



# Governors & State Legislatures in 19 states now officially recognize HCM Awareness Day



**What can we do to save and improve the lives of those with HCM?**

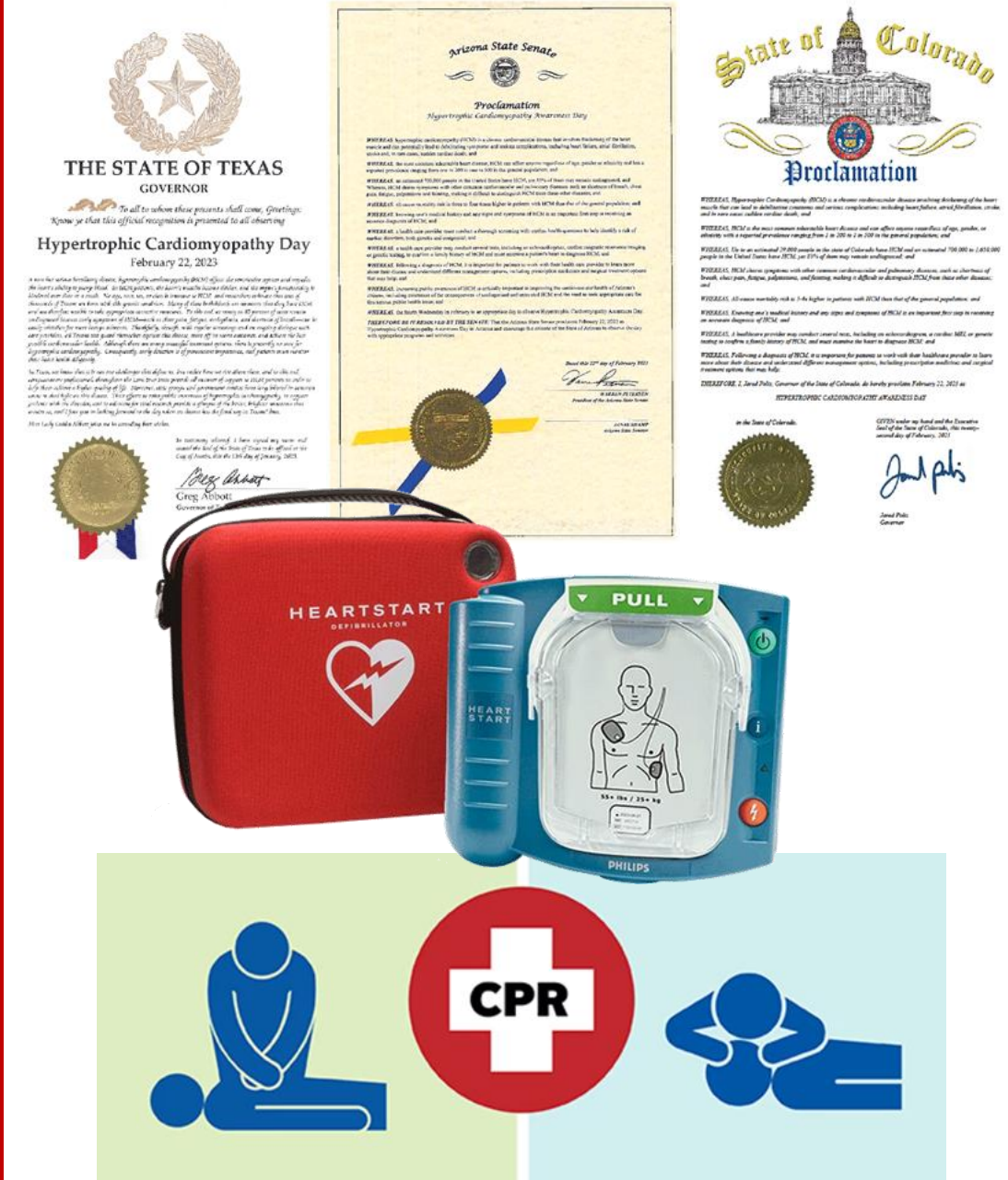


# What can you do?

1. Help pass resolutions and proclamations in your state that recognize HCM Awareness day

2. Make sure your AED/ CPR Legislation is up to date and as strong as it can be

# OR





### **Cardiac Health Spectrum of Diseases Identified in Prevalence Data:**

Hypertrophic Cardiomyopathy (HCM)  
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)  
Dilated Cardiomyopathy (DCM)  
Marfan Syndrome  
Long QT Syndrome (LQTS)  
Brugada Syndrome (BrS)  
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)  
Anomalous Aortic Origin of Coronary Artery (AAOCA)  
Congenital Heart Disease (CHD)

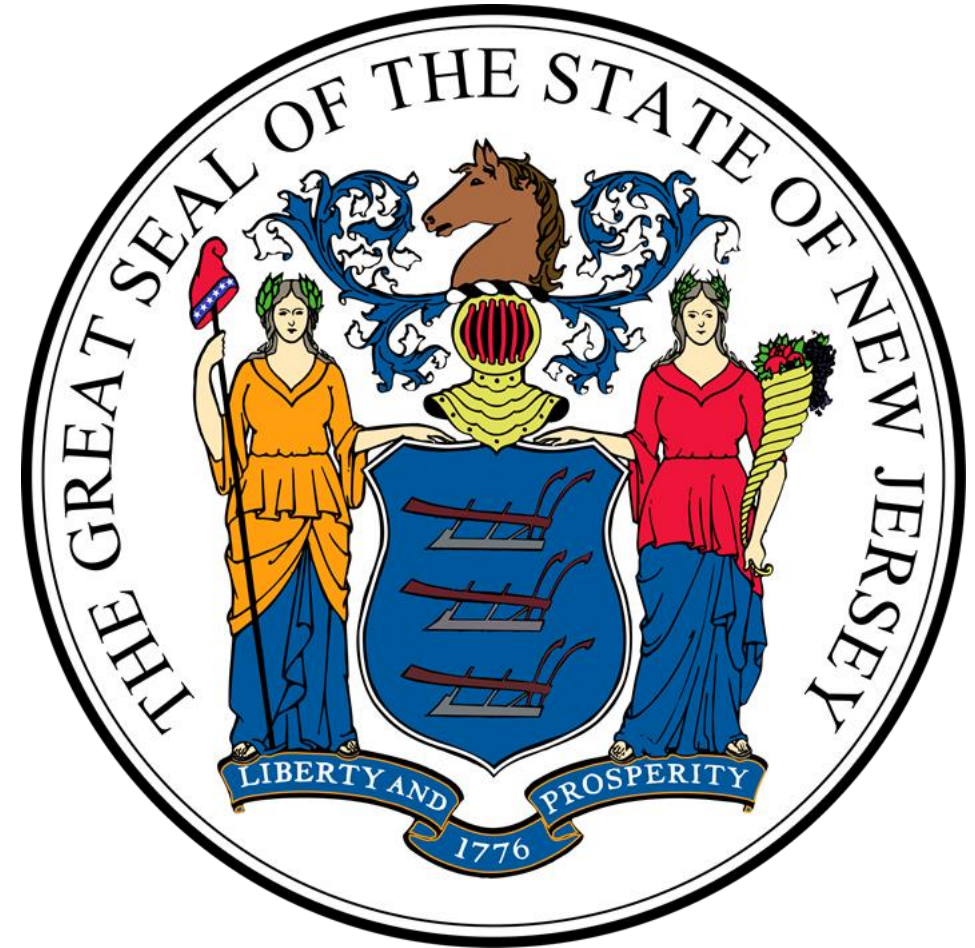
# **Become a champion for the Healthy Cardiac Monitoring ACT**

- Include cardiac questions to be added to the “Well Child” examinations for all children under the age of 19
- To improve professional development for healthcare providers with an online training system.
- Improve student-athlete pre-participation physicals and athlete education about signs and symptoms that are linked to cardiac conditions
- Improve the ability of healthcare providers to identify children and families at risk for cardiac disorders, both genetic and congenital.
- The Legislation we are seeking to introduce and pass at the level is called the “Healthy Cardiac Monitoring Act”



# Practical application?

- New Jersey adopted this in 2015
- We have seen a decrease in sudden cardiac arrests.
- We have not seen a burden on Health Care Practitioners.
- Training requirements have helped raise awareness in HCP's.
- Raises public awareness of cardiac health risks in families.



# How many families can you impact?

Example:

California- 429,703- 1,265,684

Maryland- 66,099- 194,694

Ohio- 244,564- 1,896,055

## Help us keep families whole.





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# Patient Access to Care



Making a difference at the state level – power of the patient voice and partnerships

# NEA's Current Policy Priorities



Access and Affordability	State	Federal
<b>Step therapy reform</b>	State Access to Innovative Medicines Coalition (SAIM) - 36+ states have passed legislation	Safe Step Act (S.652/H.R.2630)
<b>Out of pocket cost</b>	SAIM - actively working on state legislation - 14 states have OOP laws	
<b>Copay accumulators</b>	Copay Accumulator State Workgroup - 18 states + Puerto Rico have passed legislation	All Copays Count - HELP Copays Count (S.1375/H.R.830)
<b>Other priorities:</b> prior authorization, nonmedical switching, network adequacy, surprise billing		



# Bringing together patients and providers through coalitions:



## National Focus:

- All Copays Count – copay accumulators, state accumulator subgroup
- Safe Step Act – step therapy reform

## State Focus:

- Individual state coalitions focused on specific legislative efforts

## Positive Collaborations

- Patients and providers being at the table together
- Both willing to testify, meet with legislators and participate in media opportunities



*Example: TX organizational support – copay accumulators*

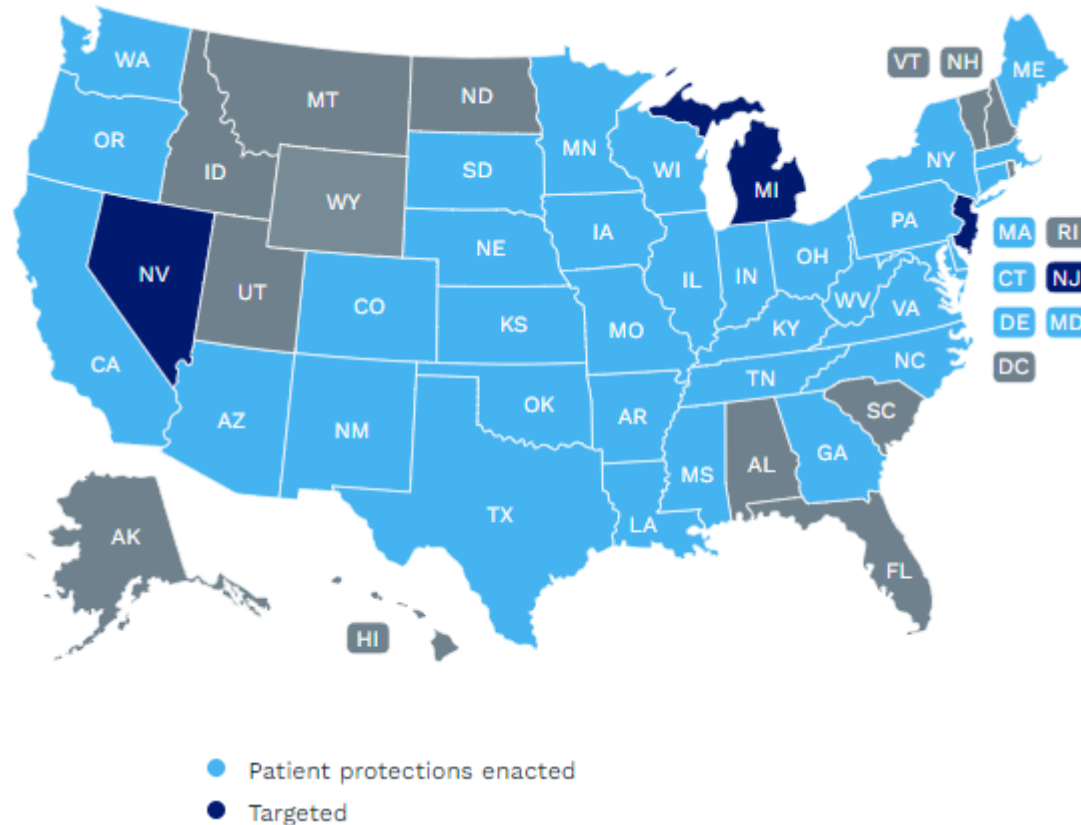
# Step Therapy Reform



Patients require by their insurer to try and fail one or more insurer-preferred treatments before the insurer will cover the treatment initially prescribed by their provider have been subject to insurer-mandated step therapy.

We want to ensure that treatment decisions are made between health care providers and patients!

***\*\*Action at federal level as well\*\****



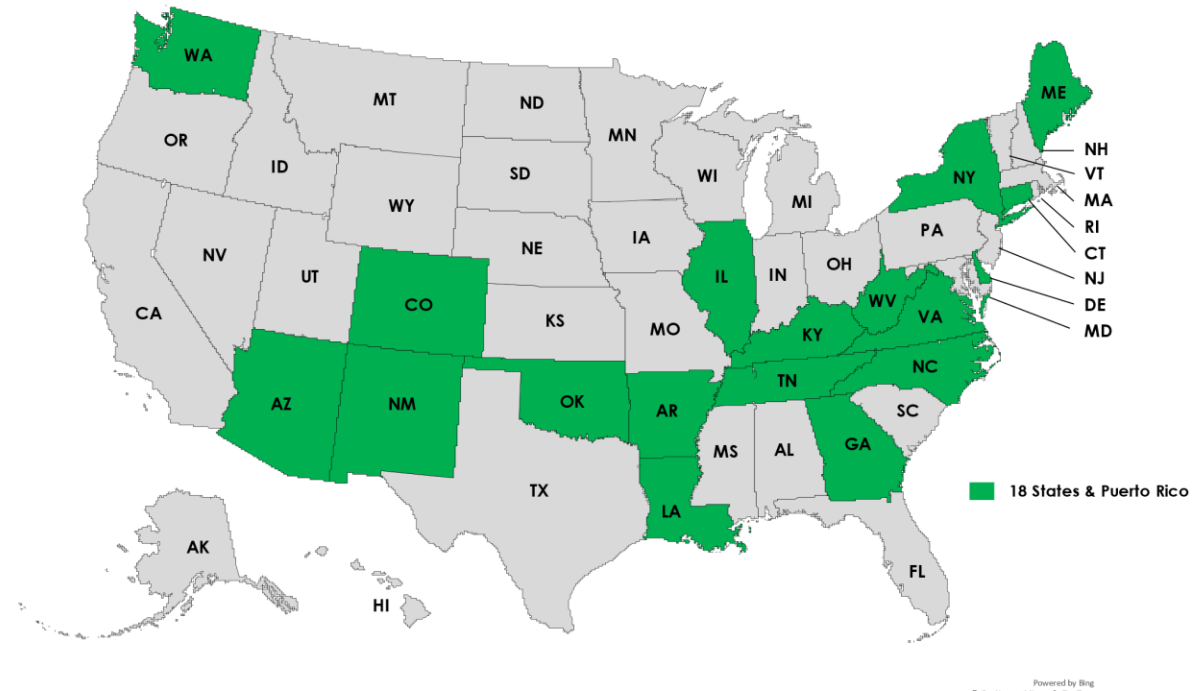
# Copay Accumulators



- Copay accumulator adjustment programs (CAAPs) cut a critical lifeline for patients and leave them exposed
- Under CAAPs, insurers have disallowed copay assistance from counting towards a patient's annual deductible and out-of-pocket maximum. But insurers are still collecting this assistance
- This results in many patients facing unexpected costs of thousands of dollars to get the medicines they need
- We want to ensure that All Copays Count!
- ***\*\*Action at federal level as well\*\****

## STATE ACCUMULATOR LAWS

June 2023







Thank you!



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