Hypertrophic Cardiomyopathy Association

Hypertrophic Cardiomyopathy Association Legislative Advocacy Toolkit

LIVING DOCUMENT last updated October 11, 2021

Preface

The Hypertrophic Cardiomyopathy Association's (HCMA) *Elizabeth T. McNamee Legislative Advocacy Committee* is seeking volunteers to work with us to improve efforts to find the undiagnosed.
In September 2021 the HCMA is beginning a national effort to:

- Include cardiac questions to be added to the "Well Child" examination 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 the 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 state level is called the "**Healthy Cardiac Monitoring Act"** (HCM Act). The complete language of this legislation appears later in this document.

As a volunteer you will:

- Participate in training – online
- Have access to online resources (***Ujoin***) that will make engagement with your legislative representatives simple.
- Potentially set up personal meetings with your representatives or appropriate State Committee members (all with support from the HCMA systems and staff)
- Encourage your friends and family to participate in advocacy through social media and use of our online systems.
- Participate in public meetings to provide testimony on why this legislation is so important to you.
- Follow up with your legislators and keep them working on passage of the HCM Act into LAW.

Next steps:

1. Please sign up to be a volunteer at https://4hcm.org/get-involved/ - choose Legislative Advocacy
2. Participate in Online training which will include how to use the software and systems.

Table of Contents

Introduction

Elizabeth T. McNamee Legislative Advocacy Committee of Hypertrophic Cardiomyopathy Association (HCMA) welcomes you as we embark together on this exciting journey of advocacy to address the cardiovascular health needs of all children, including those of student athletes in particular, and bring positive change in health policy for bettering the lives of the young patients and their families affected by cardiomyopathy.

Elizabeth T. McNamee Legislative Advocacy Committee was created in October 2019. The role of the Legislative Advocacy Committee is to carry on the legacy of Elizabeth by maintaining a policy agenda for improving legislative and regulatory initiatives on a state and federal level to further the interests of safe and progressive diagnosis and treatment of those with Hypertrophic Cardiomyopathy (HCM).

Elizabeth T. McNamee was a bright student with a wonderful future. She excelled in whatever she set out to do. Her love for people, athletics, and the arts were among her greatest attributes. She attended West Islip Schools, graduated from Harvard University with honors, and was in her final year at NYU Law School when in September of 1998 her life suddenly came to an end. Elizabeth died from undiagnosed Hypertrophic Cardiomyopathy (HCM).

Our current Legislative Advocacy Committee members include: Lisa Salberg (Founder and CEO of HCMA), Billur Dowse MS (Board of Director HCMA); Aaron Troy MD, Isaac R. Rodriguez-Chavez, PhD, MHSc, MSc (Board of Director HCMA), Lindsay Davis, and Julie Russo (Volunteer Coordinator of HCMA).

The HCMA Legislative Advocacy Toolkit was developed by the committee to educate and inform all HCMA Volunteers about HCM specific health care issues, explain state and federal level public policy, as well as the legislative process, and provide tips and resources on how to introduce and advocate for a Bill with the elected officials to bring the desired change.
The Toolkit is designed to be an introductory level tool for easy learning and helping you to be an effective voice when you choose to engage in legislative advocacy in health care policy. Taking the first step to get involved in health policy advocacy and then navigating the public policy process may seem daunting, intimidating, confusing, and you might even think it is not for you at first, however, we believe with the information provided in these pages and the resources at your fingertips you will find working on policy making process rewarding, fun and impactful.
Collectively we can bring about a change and improve the lives of the young patients and their families affected by cardiomyopathy, and together we will carry on the legacy of Elizabeth T. McNamee.

We thank you in advance for becoming involved in health policy and legislative advocacy issues advanced by HCMA. Thank you!

Hypertrophic Cardiomyopathy Association (HCMA)

ABOUT HCMA

The HCMA was founded in 1996 as a 501c3 nonprofit organization. We provide 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.

We support the creation of high volume Center of Excellence care models to ensure all needs of the HCM patient community are met at the highest possible level. We believe in improving global awareness of the risks of this genetic heart disease and ensuring disease understanding, its complete natural history, and treatments are improved until the ultimate eradication of the disease itself.

Contact Information

HCMA OFFICE:

18 East Main St.
Suite 202
Denville, NJ 07834

Phone: 973-983-7429
Fax: 973-983-7870
Web: 4hcm.org
Email: Support@4hcm.org
EIN #: **41-1855605**

KEY CONTACTS

Lisa Salberg - CEO Lisa@4hcm.org
Billur Dowse – Committee Chair - Board of Directors Btdowse@gmail.com
Julie Russo - Volunteer Services Julie@4hcm.org

Project overview Healthy Cardiac Monitoring Act" (HCM Act)

September 2021 the HCMA is beginning a national effort to include cardiac questions be added to the "Well Child" examination for all children ages 1-19, includes professional development for healthcare providers, simplifies student athlete pre-participation physicals and improves the identification of children and families at risk for genetic and congenital heart diseases.

FIND the undiagnosed! We seek to improve cardiac screening in the "Well Child" examination for all children 19 and younger, including professional development for healthcare providers, improved student-athlete pre-participation physicals, and improved identification of cardiac disorders in the young.
MOVE ACT HERE:

Hypertrophic Cardiomyopathy Association's (HCMA) Strategic Policy Agenda

HCMA provides multi-level support for people with Hypertrophic Cardiomyopathy (HCM) at the individual, family, communal, and national levels. Areas of interest and HCMA's support include: 1) advocacy work for HCM affected people; 2) education about HCM to multiple stakeholders both in public and private sectors (e.g., HCM patients and their families; biomedical community in private, not for profit, educational institutions, and public sectors; federal and state government; and the public at large).

Scientific research, medical advances, health care systems, finances, policy, and laws impact HCM patients and the work done at the HCMA. For instance, a single law can restructure our healthcare system, as well as where we live, work, and play, in ways that save or improve countless lives. To harness this power for the benefit of HCM patients and their families, HCMA both advances specific legislation and supports policies consistent with our mission and values which are described below.

- **HCMA's Mission—** To provide support, advocacy and education to patients, families, the medical community and the public about HCM, while supporting research and fostering development of treatments for diseases in the HCM spectrum.

- **HCMA's Values—** To be the pre-eminent organization enabling improvement on quality of life for those with HCM, preventing untimely deaths and advancing global knowledge.

HCMA's Strategic Priorities

Improving heart disease surveillance. HCMA supports policies that:

- Identify patients with HCM and share resources with them to ensure access to evidence-based care
- Define, diagnose and treat, structural heart conditions using sustainable, evidence-based clinical methods
- Encourage clinical screening methods for children and adults within traditional and novel care health care and clinical research models, e.g. in-person and telehealth wellness exams
- Encourage genetically based methods for the eradication of HCM within families.

Protecting against sudden cardiac death. HCMA supports policies that:

- Implement automated external defibrillator (AED) placement, training, drill, and maintenance programs in schools, governmental buildings, businesses, athletic fields, and other public areas
- Require cardiopulmonary resuscitation (CPR) training (e.g. hands-only) for high school and university students as a prerequisite for graduation
- Protect Good Samaritan status for those who use AEDs and perform CPR

Ensuring access to high quality and affordable healthcare. HCMA supports policies that:

- Protect the welfare and rights of those with preexisting medical conditions or genetic pre-dispositions to access healthcare
- Prohibit discrimination based on pre-existing conditions, demographic and socioeconomic data in premium calculations

Protecting patients from harm. HCMA supports policies that:

- Protect patients taking prescription medications, using implantable medical devices from harm, or undergoing novel genetic-based treatments
- Encourage high volume treatment models that have proven track records of improved outcomes and higher quality of life

Addressing inequity in access to, participation in, and utilization of clinical research and health care systems. HCMA supports policies that:

- Include people from all backgrounds (race/ethnicity, age, gender, socioeconomic status, geographic location) in:
    - Performance of novel clinical research
    - Implementation of biomedical innovation
    - Qualification and utilization of health care systems

Funding medical research. HCMA supports policies that:

- Ensure that federal funding for medical research on chronic heart conditions is maintained, increased, allocated to relevant areas to address the health needs of HCM patients, and represents the population impacted by these conditions

Supporting family caregivers. HCMA supports policies that:

- Help unpaid caregivers who dedicate their time and energy to loved ones with HCM and related diseases or complications
- Provide services to families to ensure their needs are met, physically, emotionally and spiritually

Improving health and biomedical education. HCMA supports policies that:

- Increase patient, provider, and public understanding about HCM and related conditions and complications, including detection, prevention, treatment, and protection

Advancing the HCMA mission and values. HCMA supports policies in addition to these specific priorities that align with the mission and values outlined above and have the potential to improve health and quality of life in the HCM community. If you have legislation you would like HCMA to support, please email support@4hcm.org. For more information, visit our website www.4hcm.org and legislation page.

Value of Advocacy in Supporting and Advancing HCMA's Policies and Programs

Advocacy is a process by which an individual or group aims to influence public policy and the allocation of resources. Policy advocacy makes use of facts, data, and personal experience as its foundation to effect change. Advocacy is essential to supporting and advancing HCMA's strategic policy agenda, its mission, values, and objectives.

Public policy and advocacy for advancing needed care, screening, diagnosis, treatments and improved health care for all who need it have been incorporated in the missions and principal activities of many health and consumer-based organizations for decades. We have all seen the positive impact of the HIV/AIDS activism of the 1980s and the breast cancer movement of the 1990s. Since then, much impactful advocacy work regarding education, disease awareness, screening, diagnoses, and treatments has positively touched the lives of many patients with asthma, diabetes, heart disease, stroke, cancer and other chronic diseases, as well as genetically inherited diseases and orphan diseases. For health issues to begin to receive the attention, public policy response, and funding they deserve, patients, parents, caregivers, guardians, friends, loved ones, and dedicated volunteers like you must engage in proactive and meaningful advocacy efforts to help derive the awareness. Policymakers and elected officials are the ones who ultimately influence issues that affect treatments, research, care options, and funding. Lawmakers then deliver decisions that impact all our lives, our healthcare needs, how healthcare is delivered, treatment costs, access, and affordability. These decisions sometimes are made with limited evidence-based facts, knowledge, and understanding of the people and systems they are affecting. ***Your Voice Matters!*** Lawmakers and your elected officials are most responsive to people from their own states and communities, and they must hear from the people who elected them and who they represent about their priorities and concerns.

Becoming a policy advocate empowers HCMA Legislative Advocacy Volunteers (and others!) to help improve global awareness of the risks of hypertrophic cardiomyopathy (HCM), ensuring disease awareness of this genetic heart disease, all the while helping to educate patients, families, the medical community as well as the public on the needed screening, diagnosis and treatment options. To achieve system-wide changes for ensuring the cardiovascular health needs of all children are met, including those of student athletes in particular, advocacy at state level and then at federal level is essential. ***We need your help to lend your voice and have your voices heard*** by your lawmakers and elected officials so they can effectively understand the HCM and cardiomyopathy spectrum of diseases, the priority problems, and recommended solutions. In order to address the concerns effectively and properly, they need medical experts and our input, so they become informed decision-makers as it pertains to the needs in their communities regarding cardiovascular health and the ramifications of changes in policy.

A patient, parent, caregiver, and a friend who is a well informed, articulate, passionate legislative advocate, can be a valued resource to elected officials and their staff for bringing issues of importance to their attention and help craft and implement necessary solutions. ***Together, we can ensure the cardiovascular health needs of all children are met, including those of student athletes. They need our support, our voices, and our commitment to help protect their future.***

What is Health Policy Advocacy?

“Advocacy is the act or process of supporting a cause or proposal” as defined by Merriam-Webster dictionary.

Advocacy is not complicated. Parents engage in advocacy every day on behalf of their children. Caregivers engage in advocacy on behalf of their loved one’s healthcare.

Advocacy is simply the process of influencing people to create change. Health Policy Advocacy is a strategy to influence policy makers when they make laws and regulations, distribute resources and make other decisions that affect peoples’ lives. When trying to gain political commitment, policy support, social acceptance and systems support for a particular public health goal or program, a combination of individual and social actions may be used to try to affect change. The good news is that health policy advocacy doesn’t require new skills, it just involves applying existing skills in an organized way in a new context. Goals and objectives that are specific, measurable, achievable, and realistic need to be set and immediate opportunities and obstacles for how to achieve these goals and objectives need to be identified.

Remember, advocacy is our right and responsibility. Advocacy is participating in the democratic process by taking action in support of a particular issue or cause and telling our legislators what we want. As USA citizens we vote to elect the policymakers. Policymakers work for their citizens from their local communities and states. In the United States we have a participatory democracy and representative government, and the first amendment in the United States Constitution allows us to become involved and address our issues. Policy makers need to learn from our expertise and stories in order to address the needs of the young patients and their families affected by cardiomyopathy.

1 United States Constitution, 1st Amendment, "Congress shall make no law respecting an establishment of religion, or prohibiting the free exercise thereof; or abridging the freedom of speech, or of the press; or the right of the people peaceably to assemble, and to petition the government for a redress of grievances."

How to Engage in Health Policy Advocacy?

Importance of Patient Voice in Advocacy

Patients who are knowledgeable about their disease and are equipped, empowered and engaged in playing an active role in their own care, partnering with their healthcare providers and even in the design of their care are proven to have better quality of life evidence and outcomes. As a patient, as a family member, or as a caregiver the most effective voices and the most valuable tool in advocacy is your “personal story”. By being able to share how you’ve been impacted by your health condition, how you and those around you have been affected with the unmet needs, and how the health care system and other related factors have impacted your care, is very powerful. You are naturally equipped to be the best advocates to voice your concerns and needs regarding your care. *We need to have these powerful effective voices heard and individual stories told so the policymakers could gain awareness of these cardiovascular health needs accurately and advance necessary policy and legislative changes to positively impact all of our lives*.

In addition to “your story” or beyond championing many stories on behalf of the patients, effective communication with policymakers, when to speak and how to deliver a specific policy ask are all components

of being an effective advocate. The specific policy ask could include an ask related to policymaker supporting a specific bill, introducing a new bill or enhancing an existing bill. A specific ask could be an ask for policymakers to learn more about the health condition/disease or a particular challenge faced by patients and work to create a legislative solution, or an ask could be related to funding for research or a particular program. With proper training, tips and resources, volunteers like you become effective patient advocates and engage in communications with policy makers to address many unmet needs of the cardiomyopathy patients and their families, educate them on the disease and the impact cardiomyopathy spectrum of diseases have in their communities if the needs are not addressed.

How to be Effective in Health Policy Advocacy

There are several methods by which patient advocates can express themselves. If you can write a letter, send an email, make a phone call or leave a brief phone message, just like you do in your everyday life to conduct business or communicate with your friends or family, you can do health policy advocacy. It is that easy.

Before we jump into these methods, we would like to introduce you to the critical "*Rules of Advocacy*", so you are successful and effective whichever method you choose to contact the policymakers, elected officials and their staff.

1- Get to know legislators well ‑ their districts and constituencies, voting records, personal schedules, opinions, expertise and interests. Be sure to have a good understanding of the legislator and his/her concerns, priorities and perspectives.

2- Acquaint yourself with the staff members for the legislators, committees and resource officials with whom you will be working. These people are essential sources of information and have significant influence in some instances in the development of policy.

3- Identify fellow advocates and partners in the public health community to better understand the process, monitor legislation, and assess strengths and weaknesses. Finding common ground on an issue sometimes brings together strange bedfellows but makes for a stronger coalition.

4- Identify the groups and other legislators with whom you may need to negotiate for changes in legislation. Do not dismiss anyone because of previous disagreements or because you lack a history of working together. "Yesterday's opponent may be Today's ally."

5- Foster and strengthen relationships with allies and work with legislators who are flexible and tend to keep an open mind. Don't allow anyone to consider you a bitter enemy because you disagree.

6- Be honest, straightforward and realistic when working with legislators and their staff. Don't make promises you can't keep. Never lie or mislead a legislator about the importance of an issue, the oppositions' position or strength or other matters.

7- Be polite, remember names and thank those who help you - both in the legislature and in the public health advocacy community.

8- Learn the legislative process and understand it well. Keep on top of the issues and be aware of controversial and contentious areas.

9- Be brief, clear, accurate, persuasive, timely, persistent, grateful and polite when presenting your position and communicating what you need/want from the legislator or staff member.

10- Be sure to follow up with legislators and their staff. If you offer your assistance or promise to provide additional information, do so in a timely and professional manner. Be a reliable resource for them today and in the future.

Communicating with Policymakers

Now let's review the several methods by which patient advocates can express themselves and communicate with the policymakers, elected officials and their staff.

- **Letters and emails to elected officials.** Call to action emails that come from advocacy organizations (like the HCMA) in which individuals can click and send communications to legislators using ***Ujoin*** (an easy-to-use interface for advocates to reach their intended audiences via testimony or letter-writing campaigns with just a "click"). ***Ujoin*** is available on our 4hcm.org website.

- **Social media.** It has become increasingly common for constituents to tag their lawmakers in public messages on Twitter and other platforms asking them to take a particular action.

- **Meetings.** Meetings with elected officials in the state or county offices at the lawmaker's home district or for federal level interactions at the capitol office of the lawmakers. Any constituent can reach out to their elected official to request a meeting. Working with the HCMA office we can often help coordinate such meetings and help prep people to tell their story and make an ask.

- **Calls to elected officials**. While it's unlikely that callers will be put through to speak directly with the official, calls convey an urgency to an issue, and the staffer answering the phone will take a message registering your opinion and ask. Calls can be made via ***Ujoin*** as well and are specially impactful when trying to push for final passage of a bill around the time it's being schedule for a vote — or when trying urgently to stop a bill from passing.

- **Testifying at a legislative hearing or briefing**. Often, before a Committee in the House or Senate debates a particular bill (both at the State and Federal level), they will hold hearings on the topic to hear from experts to learn more. In many cases, patients may be invited as witnesses to tell their stories. In other cases, lawmakers and advocacy groups will host briefings in the State House and/or Senator or at the Capitol on a particular topic — these are less formal than Committee hearings, but still offer the opportunity for lawmakers and their staff to hear from experts and to learn more.

- **Letters to the editor**. In some cases, advocates want to reach an audience beyond the lawmaker or they want to apply pressure publicly, so they submit letters or editorials to the local newspaper. In these instances, the goal is often to appeal to other members of the community to support your cause so that they will join in applying pressure to the lawmaker.

- **Submitting public comments**. In the case of administrative rulemaking, advocates have an opportunity to influence the final rule through the comment process. All types of stakeholders, including ordinary citizens, are welcome to provide their perspective and opinion about the proposed rule through a written comment submitted to the State or Federal Register.

Overview of United States Civics

Essentially, civics is about what citizens of a nation can do. When you are a citizen, you are considered part of the nation and have an active role in determining what that nation does. We, as citizens, usually think of voting when we think of civics.

Laws and policies at the federal, state and local levels impact many aspects of our lives, including our health. They influence investments in medical research and public health, the administration of Medicare, Medicaid and other health insurance programs, the safety and efficacy of medication and devices that are allowed on the market, and more.

Overview of State Level Legislation

State legislatures serve three primary functions. They **perform a lawmaking function by researching, writing, and passing legislation**. Members represent their districts and work to meet requests for help from citizens within it. Finally, legislatures perform an oversight function for the executive branch. The word legislature comes from the Latin word for "law" — legis. In the US, each state has a legislature — made up of the elected state senators and assemblymen or women, or representatives.

State Government

All State governments are modeled after the Federal Government and consist of three branches: executive, legislative, and judicial. The U.S. Constitution mandates that all States uphold a “republican form” of government, although the three-branch structure is not required.

<u>Executive Branch</u>

In every state, the Executive Branch is headed by a governor who is directly elected by the people. In most states, other leaders in the executive branch are also directly elected, including the lieutenant governor, the attorney general, the secretary of state, and auditors and commissioners. States reserve the right to organize in any way, so they often vary greatly with regard to executive structure.

Legislative Branch

All 50 States have legislatures made up of elected representatives, who consider matters brought forth by the governor or introduced by its members to create legislation that becomes law. The legislature also approves a State's budget and initiates tax legislation and articles of impeachment. The latter is part of a system of checks and balances among the three branches of government that mirrors the Federal system and prevents any branch from abusing its power.
Except for one State, Nebraska, all States have a bicameral legislature made up of two chambers: a smaller upper house and a larger lower house. Together the two chambers make State laws and fulfill other governing responsibilities. (Nebraska is the lone state that has just one chamber in its legislature.) The smaller upper chamber is always called the Senate, and its members generally serve longer terms, usually four years. The larger lower chamber is most often called the House of Representatives, but some states call it the Assembly or the House of Delegates. Its members usually serve shorter terms, often two years.

Judicial Branch

State judicial branches are usually led by the State supreme court, which hears appeals from lower-level State courts. Court structures and judicial appointments/elections are determined either by legislation or the State constitution. The supreme court focuses on correcting errors made in lower courts and therefore holds no trials. Rulings made in State supreme courts are normally binding; however, when questions are raised regarding consistency with the U.S. Constitution, matters may be appealed directly to the United States Supreme Court.

Key Types of Legislation

Each state in the United States has a legislature as part of its form of civil government. Most of the fundamental details of the legislature are specified in the state constitution. With the exception of Nebraska, all state legislatures are bicameral bodies, composed of a lower house (Assembly, General Assembly, State Assembly, House of Delegates, or House of Representatives) and an upper house (Senate).

Bills

Bills are prefixed with H.R. when introduced in the House and S. when introduced in the Senate, and they are followed by a number based on the order in which they are introduced. The vast majority of legislative proposals are in the form of bills. Bills deal with domestic and foreign issues and programs, and they also appropriate money to various government agencies and programs.
Public bills pertain to matters that affect the general public or classes of citizens, while private bills affect just certain individuals and organizations.
A private bill provides benefits to specified individuals (including corporate bodies). Individuals sometimes request relief through private legislation when administrative or legal remedies are exhausted. Many private bills deal with immigration–granting citizenship or permanent residency. Private bills may also be introduced for individuals who have claims against the government, veterans' benefits claims, claims for military decorations, or taxation problems. The title of a private bill usually begins with the phrase, "For the relief of. . . ." if a private bill is passed in identical form by both houses of Congress and is signed by the president, it becomes a private law.
When bills are passed in identical form by both Chambers of Congress and signed by the president (or repassed by Congress over a presidential veto), they become laws.

Joint Resolutions

Joint resolutions are designated H.J. Res. or S.J. Res. and are followed by a number. Like a bill, a joint resolution requires the approval of both Chambers in identical form and the president's signature to become law. There is no real difference between a joint resolution and a bill. The joint resolution is generally used for continuing or emergency appropriations. Joint resolutions are also used for proposing amendments to the Constitution; such resolutions must be approved by two-thirds of both Chambers and three-fourths of the states, but do not require the president's signature to become part of the Constitution.

Concurrent Resolutions

Concurrent resolutions, which are designated H.Con.Res. or S.Con.Res., and followed by a number, must be passed in the same form by both houses, but they do not require the signature of the president and do not have the force of law. Concurrent resolutions are generally used to make or amend rules that apply to both houses. They are also used to express the sentiments of both of the houses. For example, a concurrent resolution is used to set the time of Congress' adjournment. It may also be used by Congress to convey congratulations to another country on the anniversary of its independence. Another important use of the concurrent resolution is for the annual congressional budget resolution, which sets Congress' revenue and spending goals for the upcoming fiscal year.

Simple Resolutions

Simple resolutions are designated H.Res. and S.Res., followed by a number. A simple resolution addresses matters entirely within the prerogative of one house, such as revising the standing rules of one Chamber. Simple resolutions are also used to express the sentiments of a single house, such as offering condolences to the family of a deceased member of Congress, or it may give "advice" on foreign policy or other executive business. Simple resolutions do not require the approval of the other house nor the signature of the president, and they do not have the force of law.

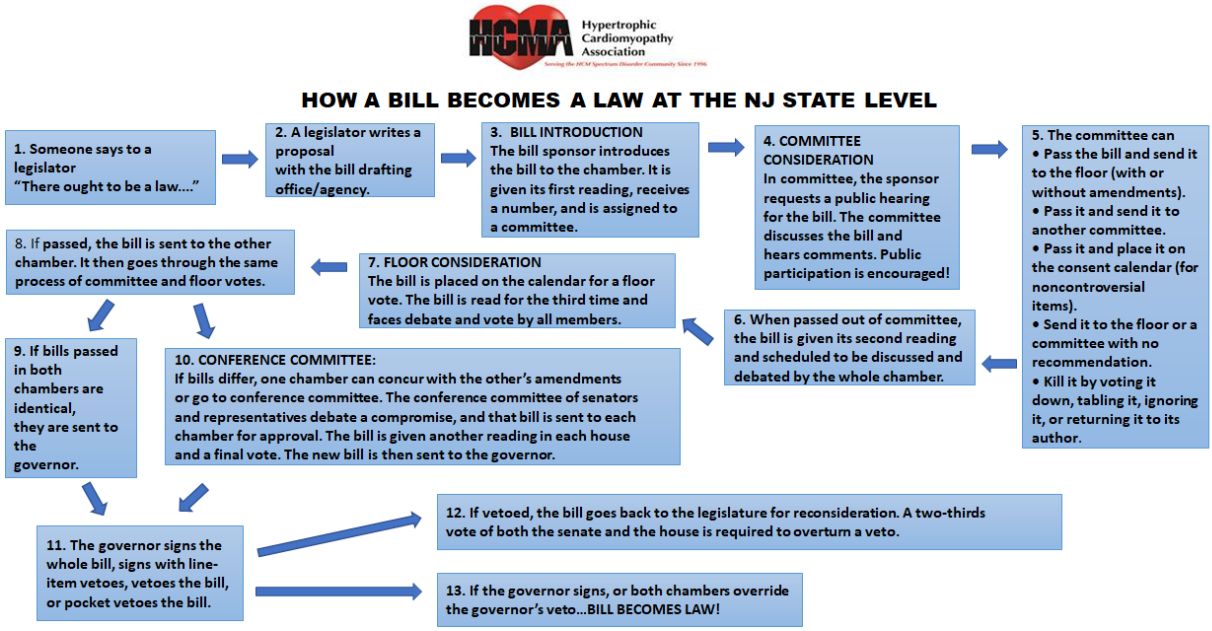
How a Laws and Policies are Made and Bill Becomes Law

Federal Level

1. Bill introduced in either house- House of Representatives or Senate House.
2. Bill is referred to a committee to discuss and decide whether to pass or not.
3. It goes back to the floor for a vote. If it passes, then the bill goes to the other house. They do the same as step #2.
4. If there have been no changes made to the original bill, it can go directly to the President. If there have been changes, the bill goes to the Conference Committee to combine both versions and then it goes back to both houses for a final vote. If it passes in both houses, then it goes to the President
5. The President can sign the bill to become law…or the President can veto which rejects the Bill or it becomes law anyway if 2/3 of the House and Senate override the veto.

State Level (vs. Federal Level)

1. The ultimate executive to sign or veto bills is the president at the federal and the **governor** at the state level.
2. At the federal level there are more members and committees to review bills. (Typically, the more members that have to review a bill -like at the federal level- will mean a greater chance for the bill to be killed. More people= harder to gain a majority to agree…so it's easier for a bill to pass at the state level, where it will affect less people than at the Federal level where bills become laws to affect the whole nation).
3. NOTE: The process for bills to become law at the state level varies from state to state. Below is a general example of the process in New Jersey.



How a Bill Becomes a Law: 13 (Initial Target) Individual State Processes

CA STATE LAW PROCESS: Legislative Process | California State Senate

IL STATE LAW PROCESS: Illinois's Legislative Process - Illinois Legislation - LibGuides at University of Illinois at Urbana-Champaign

MA STATE LAW PROCESS: legislativeprocessinmass.pdf

MD STATE LAW PROCESS: Maryland General Assembly - Legislative Process

MI STATE LAW PROCESS: SOM - How does a Bill become a Law? (michigan.gov)

NJ STATE LAW PROCESS: Student_Guidenew_2012_StudGuideCompReadhorizsprds.qxd (state.nj.us)

NY STATE LAW PROCESS: How a Bill Becomes a Law | NY State Senate (nysenate.gov)

OH STATE LAW PROCESS: How A Bill Becomes A Law | The Ohio Senate

PA STATE LAW PROCESS: Making Law PA - Ordered.pdf (pacapitol.com)

TX STATE LAW PROCESS: Texas House of Representatives - How A Bill Becomes A Law

UT STATE LAW PROCESS: Bill to Law (utah.gov)

VA STATE LAW PROCESS: How a Bill Becomes a Law | VirginiaNavigator

WA STATE LAW PROCESS: How a Bill Becomes a Law

*****While our initial effort is for the 13 states designated above, this does not mean we cannot start the process in other states!***

CLICK HERE FOR ALL STATES: Legislative Process - StateScape

Navigating State Legislative Advocacy Strategy Process

When people think of Legislative Advocacy, the majority of the people think they must engage only in Washington, DC. In reality, if we really want to see change and get things done, we should focus on state level legislative advocacy. A perfect example to demonstrate this statement is to look at the 2020 legislative sessions. "The combined statehouses across the United States introduced more than 130,000 bills and enacted over 22,000 of them. The United States Congress introduced about 20,200 bills of which only 1,063 were enacted. That's about 13 times less than the states!" (source: FiscalNote, CQ Roll Call, Washington, DC 2021)

For successful outcomes, mapping the political landscape, knowing who is who, and when to reach out to the lawmakers requires plotting a legislative strategy to advance the policy proposal that calls for action. As a general rule, individuals/volunteers should target their advocacy at their own elected officials. Senators and Representatives/Assembly members are much more open to hearing from people who live in their districts and states – their constituents, as opposed to those who live elsewhere. Constituent-based grassroots advocacy is widely considered to be one of the most effective advocacy strategies. That said, there are some occasions when a patient advocate may be called upon to share their story with other lawmakers who are important to advancing a particular policy.

Mapping the political landscape requires answers to the following questions, which are related to first understanding the history and then looking forward;

1- What is the legislative history of the issue?

2- Where were the impediments to enactment in the past?

3- Which committees have jurisdiction?

4- How can overlapping or competing jurisdictional claims be addressed?

5- Who have been the past leaders, supporters, or opponents?

6- For the new issue, have you identified the potential key supporters?

7- Who are the lead sponsors for the measure? (Focusing first on majority party members of the relevant committees, but always looking to secure bipartisan support.)

8- Do you have the voting records, speeches, relevant past positions, and discussions with staff, that can provide a foundation for selecting leaders and other supporters for the issue?

9- What is the timing for developing and introducing a bill?

10- Have you contacted the American Bar Association (ABA) for state level advocacy and harnessed input from the state and local bars? State and many local bars are the respected legal authority on issues for state legislatures, and their guidance will often be sought by state policymakers.

Grassroots advocacy is most effective when it is part of a structured, coordinated, and unified effort. While it's never the wrong time to use your voice and share your opinion with your elected officials, there are various points in the legislative process when it is more impactful to make a concerted advocacy effort and when it's important to target specific lawmakers. Here are some examples:

· ***Once a bill is introduced*** – If there is a piece of legislation that you support, ask your elected official to cosponsor the legislation (note that Representatives and Senators can only cosponsor legislation in their own Chamber). Co-sponsorship is an indication that the Member supports the bill; it's often important for a bill to have many cosponsors to gain momentum. Sometimes, all it takes is a simple ask — bringing the bill to a Member's attention — to get them to cosponsor. In other cases, it may take a more concerted effort to educate and persuade the Member to your point of view.

· ***Once a bill is being considered in Committee*** — This is a moment when advocacy efforts need to focus on Committee members, whether you're trying to advance or stop a bill. It is also a key moment to try to pass any amendments to a bill if you would like to see it altered, which is much easier in Committee than on the floor.

· ***Once a bill is moving to the floor*** — If a bill that you care about is gaining momentum after it passes out of Committee, it is critical that your elected official hears from you about whether you oppose or support the bill. Even before a bill is scheduled for debate, sometimes individual Members or groups of Members work to put pressure on the leadership to either advance or stop particular legislation. Once a bill gains momentum at the end of the legislative process — and often this means it starts to make news — your voice is more important than ever; let your elected official know whether you want them to vote yes or no.

· ***Federal Spending Legislation*** — Unlike for most bills, which can be introduced and move through the legislative process at any time, federal spending bills, known as appropriations legislation, generally move based on a set annual schedule. When advocating for federal spending on medical research or specific programs, it is important to follow the schedule and make requests with the appropriate Appropriations Subcommittees at the right time.

· ***State Budget Process*** - Even though there are variations in how each state processes spending legislation, in almost every state, proposed budgets are put together in the executive branch. Most state fiscal years run from July 1 to June 30, and governors begin the process in July or August by having their budget office's send out instructions for budget requests to the various departments and agencies. When introducing a Bill each state's specific timing and schedule needs to be followed.

How to Communicate with Members of the State Government and Legislators (e.g. State Senators, State House/Assembly Members, Committee Members, other Key Stakeholders)

Understanding how to communicate effectively with policymakers, when to speak up and how to deliver an ask are all important components of being an effective advocate. In particular for patient advocates, often your most valuable tool is your own personal story. Being able to share how you've been impacted by your health condition, how those around you have been affected and how the health care system and other related factors have impacted your care is very powerful. Personal stories can be used to motivate change when they demonstrate that there is a problem or gap in policy that must be addressed.

Therefore, in addition to your story, patient advocates are most effective when they can follow up with a specific ask. Our specific ask is to have policymakers support our advocacy bill, "**Healthy Cardiac Monitoring Act",** an act concerning the cardiac health of children and student athletes.
Beyond your own personal stories, you have the power in that you can often speak on behalf of others living with or potentially at risk of heart disease by providing statistical information on the number of constituents in a policymaker's district that are potentially at risk.

Tips for Written Communication (e.g. Letters, Fax or Email)

When writing or faxing a letter to your legislator, use the proper salutation, for example:
The Honorable (first name) (last name)
Address
City, State, Zip code
Dear (Assembly Member / Senator) (last name)

Be courteous and informative in your communication. State the purpose of the letter in the opening sentence and if you are referring to a bill, include the bill number, author and topic. If you live in the elected official's district be sure to say this in the opening paragraph as well. Focus on the message and key points. Personalize the letter by including examples of how the legislation might impact you and your family. Keep the letter brief – not more than one page.Restate your request at the end of the letter, for example urging them to support the bill. Provide data to support your position. Thank the legislator for his or her support and offer to address any questions that he or she might have. Be sure to include your contact information, and sign the letter.

Sample Letter for Writing, Emailing or Faxing your Legislator

While you will be able to access preformulated written communications to legislators via *Ujoin* through our 4hcm.org website, the letter will look similar to the example below.

**(Month) (Day) (Year)

The Honorable (First name) (Last name)
(Room Number), State Capitol
Sacramento, CA (Zip Code)

RE: (state the topic or include the bill number, author and subject if you are writing to support or oppose a particular legislative bill)

Dear (Assembly Member/Senator) (Last name):

My name is (your first and last name) and I am a (Choose: regional center consumer family member/service provider/advocate/community member) who resides in your district.

(State why you support or oppose the bill or other issue here. Choose up to three of the strongest points that support your position and state them clearly.)

(Include a personal story. Tell your representative why the issue is important to you and how it affects you, your family members and your community.)

(Tell your representative how you want her or him to vote on this issue and ask for a response.

Be sure to include your name and address on both your letter and envelope.)

Sincerely,

SIGN YOUR NAME
Print your name
Street address
City, State, Zip code**

Emailing Your Legislator

When sending email communication to a legislator, the same guidelines apply to email as to written letters. Before sending an email, you might want to call the legislator's office and ask if a letter sent by e-mail is effective. If you do send an email, send it to the representative. Do not copy other representatives or send a mass email. Make it a brief message with no special layouts or graphics. Do not include attachments. Include your full name and address so it is clear that you are a constituent, and ask for a response. You might also want to send a hard copy of your e-mail to the legislator.

Tips for Calling State Legislators & Their Staff

When calling a lawmaker's office, **be prepared to deliver a succinct message**. ***Example: My name is Suzy Smith, I live in your district and my family has been impacted by a genetic heart disease called Hypertrophic Cardiomyopathy, (HCM) and we need to discuss how to help the other 10K people in our district diagnosed before it's too late.*** You will likely get very little time to leave a message so be clear and to the point. It is quite unlikely that the staffer will ask you anything more than where you live (to determine if you're a constituent), so don't worry about needing to have many prepared responses to questions.

When making phone calls to a legislator, state your name and address and identify yourself as the legislator's constituent. You will often be speaking with a secretary or aide. Briefly make known your position as they keep track of the issues that people call about to report to the legislator. Have your thoughts organized in advance, which will help you to keep the call brief and to the point. It is also very helpful to share how the issue affects you personally. Thank them for their support.

Tips for Meeting with State Legislators & Their Staff

When meeting in person with a lawmaker (or their staff), **come prepared**.DEFINE PREPARED Think about what story you want to tell and what ask you want to make. While it's best to be authentic (don't read a script in the meeting) and to be flexible (e.g. the meeting may only last 15 minutes when you were expecting 30 minutes), it's also important to determine ahead of time the key messages or points you want to deliver. For any number of reasons, meetings can sometimes get off track. It is helpful to have something concrete to return to so you walk out of the meeting confident that you at least delivered your message and made your ask.

Setting up a Meeting

Your members of Congress (United States Senators and Representatives) make time for meetings with constituents as part of their duties as elected officials. Face-to-face meetings are one of the most powerful ways to advocate, as a meeting makes you and your issue more memorable to legislators. It is important to know that the staff who work for members of Congress are very important, too! Whether you meet directly with your Senator or Representative or with their staff person, you are taking an important step by building a relationship with them. This makes them much more likely to pay attention when we call or email about a specific issue in the future. You can set up a meeting by following the steps below.

- Find out when the legislator will be back in the district. While the legislature is in session, your senators and representatives will be in Washington, DC. While the legislature is in recess, they will likely be back in their local offices. You can check your senators' and representative's websites to find out when they are on recess. While not essential, the best time to request a meeting with a lawmaker is when they are back home in the district.
- Request a meeting. Most legislators' websites include a "Request for Meeting" form that you can fill out online OR offer an email address for the person in charge of scheduling their appointments. Before calling your lawmaker's office, fill out the form or send an email request for a meeting. If you are sending an email, it should contain the following:
    - Your name and address (to show that you are a constituent)
    - The issues you wish to discuss and the local office you wish to visit
    - The dates that you can meet (include several dates or a wide time frame so that there is flexibility in scheduling the meeting)
- Follow up your request with a phone call. A day or two after you anticipate your communication has arrived, follow up with a phone call to your legislator's local office. Ask for the person in charge of scheduling your lawmaker's appointments.
- Write down the date, time and person you spoke with. If you have not heard back in a few days, call again to follow up. Be polite but persistent!
- Recognize that you might meet with a member of your legislator's staff. Sometimes legislators may not be available and you will be scheduled to meet with a member of their staff. This is still a wonderful opportunity! Legislators rely heavily on their aides to make decisions as aides are policy experts. Your meeting with a staff member can inform his/her recommendations to your legislator and also build an important relationship with your lawmakers' office.
- CONFIRM YOUR APPOINTMENT The day before your meeting, call your legislator's local office to confirm your appointment. Your legislator's office may request a list of those who will be attending the meeting, if there are attendees other than yourself.

Thank you & Follow-up Letters to State Legislators & Their Staff

FOLLOW UP YOUR MEETING WITH A THANK-YOU After your meeting, be sure to send a thank-you letter to your lawmaker and/or your lawmaker's staff. Thank them for taking the time to meet with you and re-iterate the ask that you made in your meeting. Your legislator and his/her staff will appreciate it – and it is a great way to remind them about your requests! Thank you letters will be available using ***Ujoin*** via our website as well!

Tips for Being Effective Advocacy Volunteers

While constituents who present their views and personal stories to lawmakers are not expected to be policy experts or professional lobbyists, they will be much more effective if they present clear, well-informed messages. Members of Congress, state lawmakers, committee members receive hundreds if not thousands of messages a day, and often their staffers are responsible for reviewing all the mail, social media messages and serving as a gatekeeper for meeting requests. HCMA has provided you with key messages, form letters, sample emails, call texts, medical information, and data related to cardiomyopathy. As Advocacy Volunteers, who completed their training, you have access to all these resources at your fingertips.

All throughout this training manual, we provided you with individual suggestions and tips on how to be effective advocacy volunteers. It is worth mentioning the specific two sections of this document titled "How to be Effective in Health Policy Advocacy" and "How to Communicate with Members of the State Government and Legislators". In the last chapter of this training manual, we wanted to highlight and leave you with the key tips for being effective and how to get your messages noticed by lawmakers.

1. ***Organization and partnering with HCMA Staff and Legislative Advocacy Committee Members is key***: You are not alone on this journey. Even if you have a great idea, don't go at it alone. HCMA has all the tools and resources you need at your fingertips.

2. ***Connect your state advocacy strategy to personal stories –*** The most powerful advocacy comes from people and their stories. Personalize the HCM disease, the issues of the unmet needs by sharing your own story with your legislator. It makes the issue real and helps them understand how their support can improve the lives of people living with HCM as well as their families and their caregivers' lives. HCMA staff will help you organize your story and deliver it effectively to your legislators so they can see the real need and the reason why you are introducing the **H**ealth **C**ardiac **M**onitoring **A**ct.

3. ***Be clear from the start what issue you are addressing and why it is important to you.*** HCMA is providing you with form letters, email samples, and phone call texts for you to use. These tools clearly highlight the issue, reference the **H**ealth **C**ardiac **M**onitoring **A**ct you are introducing, and its importance. If you choose to write an additional message in your own words or adapt a form letter as appropriate (approved by HCMA) to get the lawmakers' and their staff's attention, make sure you include the name of the Act, any reference numbers, and concisely state why the issue is important to you. Be clear with your ask and briefly provide reasons for your position. Your position, whether it's informed by personal experience or a description of how this policy will impact the lives of the people in that particular state, should be factual and supported by data. HCMA has provided you with the resources you need.

4. ***When calling a lawmaker's office or meeting with them, be prepared to deliver succinct messages and come prepared.*** HCMA has provided you with the tools you can use as "leave behind" resources. You will likely get very little time during a call or a meeting. Study the resources and materials provided to you by HCMA in advance so you can deliver to-the-point clear messages. Advance preparation is critical prior to meeting with the lawmakers. Think about what story you want to tell and what ask you want to make. While it is best to be authentic (don't read a script in the meeting) and to be flexible (e.g., the meeting may only last 10-15 minutes when you were expecting 30 minutes), it is also important to determine ahead of time the key messages or points you want to deliver. For any number of reasons, meetings can sometimes get off track. It is helpful to have something concrete to return to so you walk out of the meeting confident that you at least delivered your message and made your ask.

5. ***Contact HCMA Staff and let them know when you have spoken to or heard from your legislators*** so that we can further follow up with their offices and support you with this critical endeavor we jointly embarked on. Building a year-round state advocacy schedule is critical to keep our issues top of mind for legislators. Remember they are relying on us for information, many states do not have research staff, so basically, we are helping lawmakers to tap into our resources which are based on facts and accurate data.

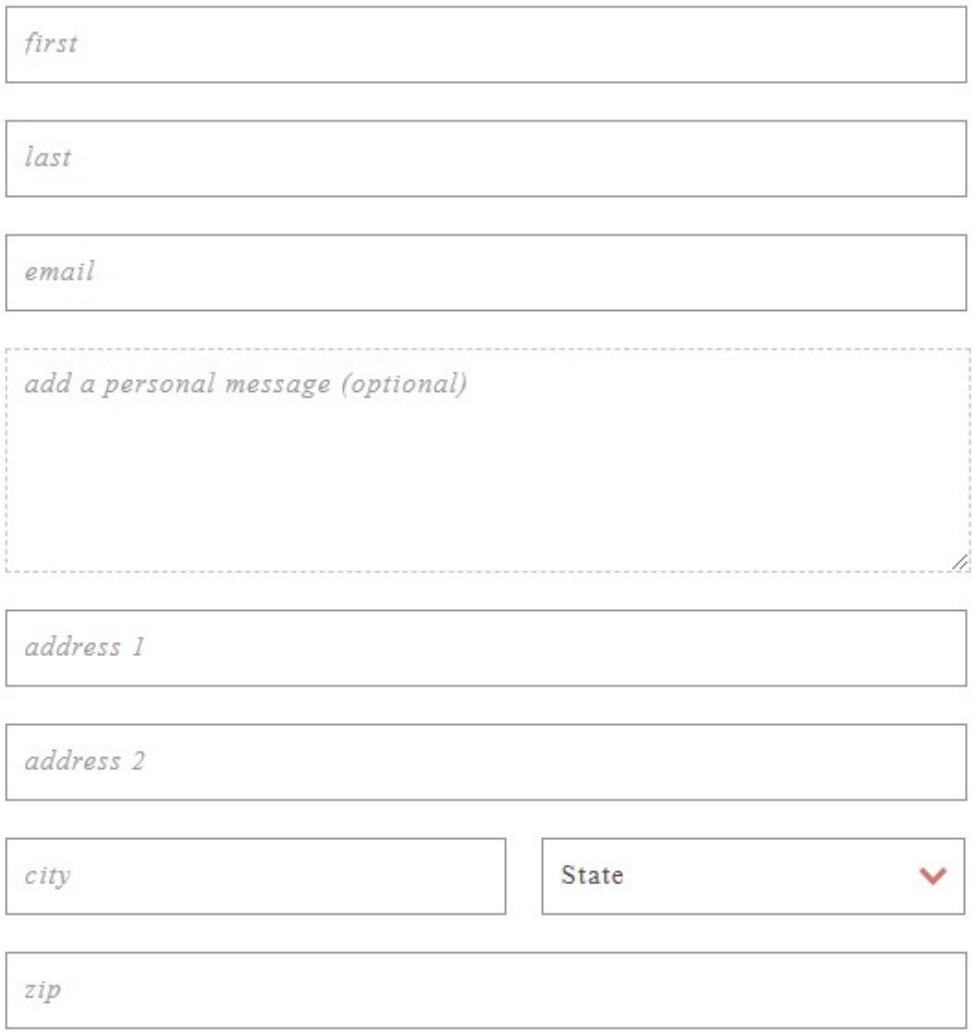
About U-Join

Ujoin is an online advocacy platform that delivers an easy-to-use interface for advocates to reach their intended audiences. The **Ujoin** platform will allow us to send targeted email campaigns to state lawmakers in order to show support of our legislative initiative, the "**Healthy Cardiac Monitoring Act".** Showing support using **Ujoin** is done with just a couple of "clicks" from our website**. Ujoin** will also allow us to track bills as they advance. To use Ujoin:

1. **Visit our Ujoin page to act today and send a letter:**
   Visit our Ujoin action page and email your state representatives - educating them about the *Healthy Cardiac Monitoring Act*.

   The action page is: https://ujoin.co/campaigns/1453/actions/public

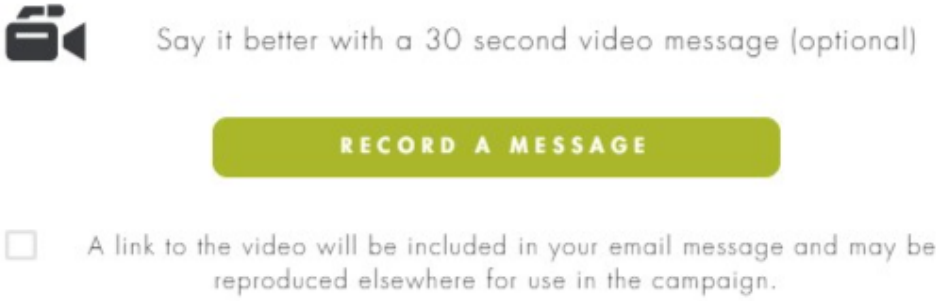
   A. **Enter your demographic information** including first name, last name, city, state, and zip code.



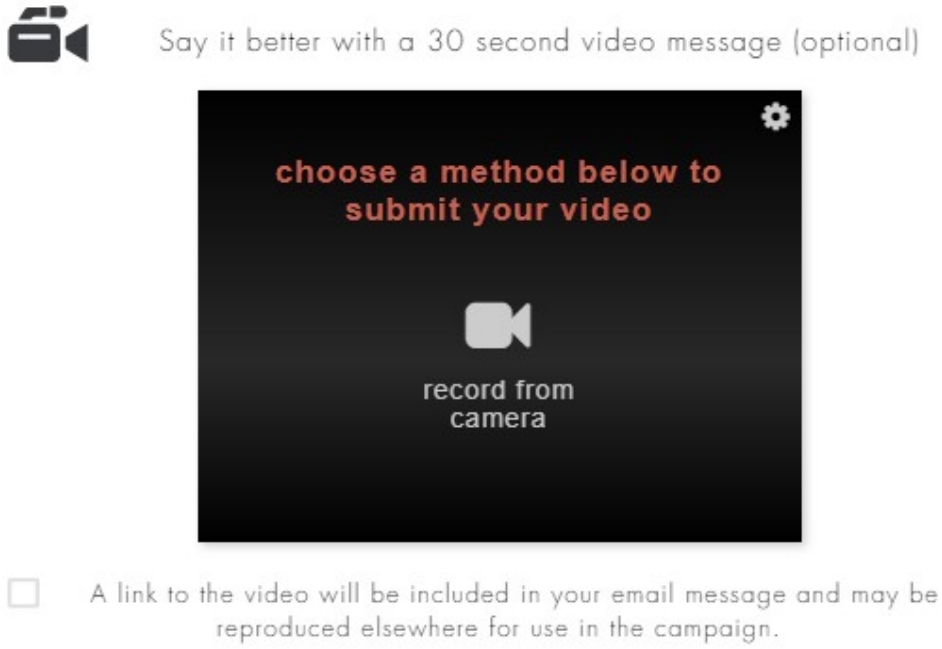
B. **Write a personal message.** How do you feel early childhood screening would have changed your life or can potentially save a life in your community. Making a personal case for the introduction of legislation makes a powerful impact.

C. **<u>Record a 30 Second Video</u>**<u>: There are a few steps prior to recording.</u>
(Video messages are optional but are very effective ways to share your motivation for seeing a bill passed) *If you are not recording a video you may skip to letter D*

☐ If you would like to record a video click on **Record A Message**

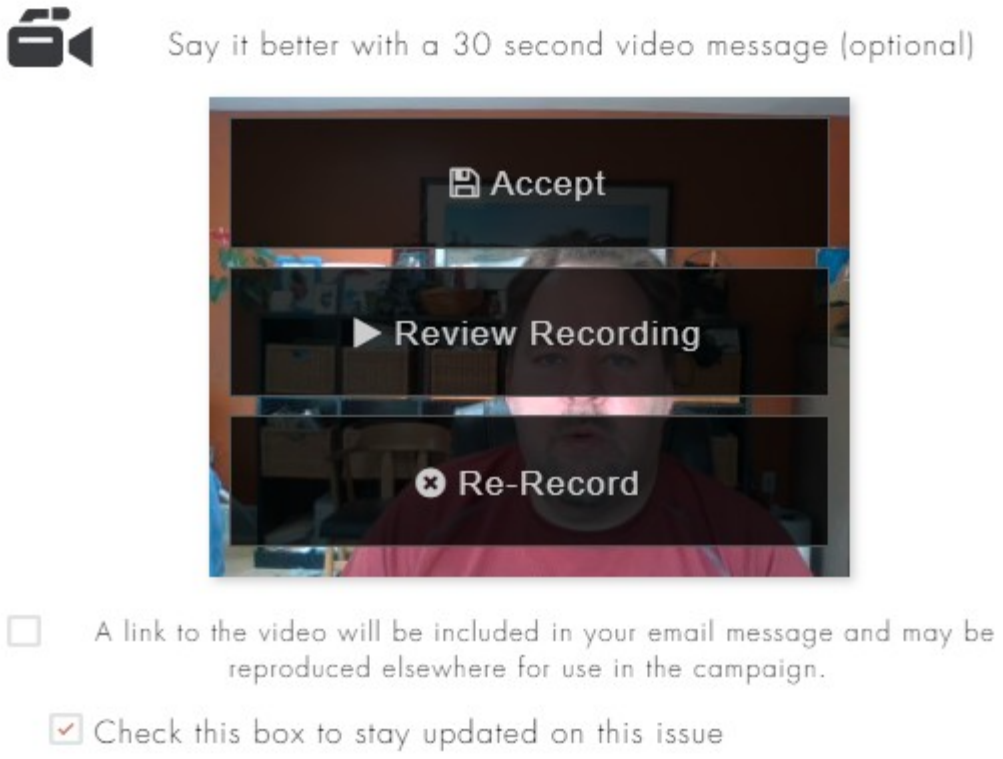


☐ **Next, click on the record from camera icon that has appeared on the small black screen**



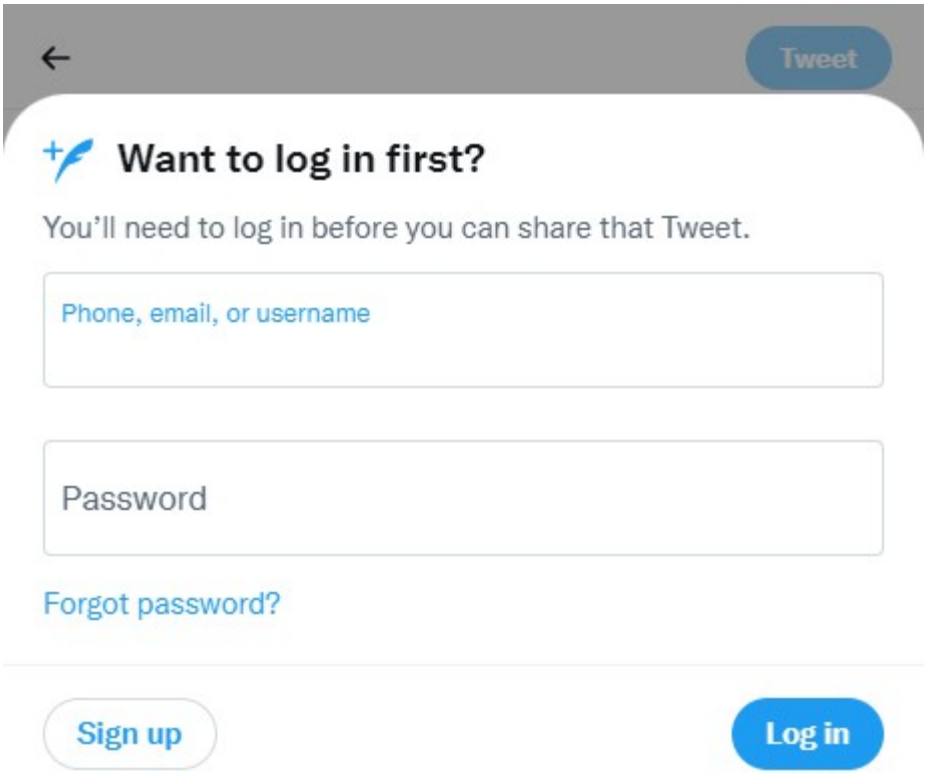
☐ **Now, click on allow the use of camera and microphone (Pop up window)**

☐ **The video recorder will count down prior to recording.**
(Don't worry you get the ability to review and rerecord as needed.)



D. <u>If you don't use Twitter you can now select "Send Email"</u>

E. If you use Twitter - click on the Tweet button and follow the login screen

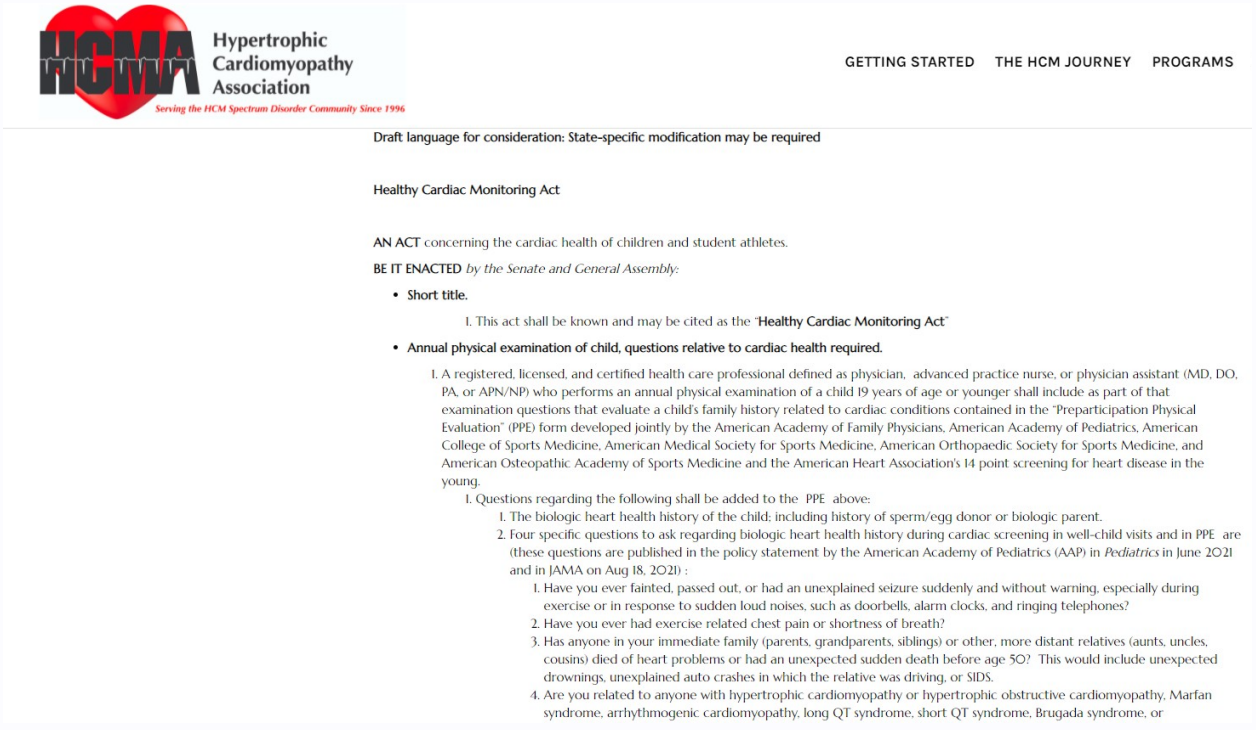


F. <u>Enter your Tweet and return to send your email and post</u>

2. **After you have sent your email and/or Tweet, please share the Ujoin link:**
   You have seen how viral marketing works on social media - it is your turn to make something good spread and help support early diagnosis. We want to encourage those in power to *Write a bill... Pass a law... Save a life.*

   Sharing the link with your friends, family and asking them to sign and share is the best way to reach those who can make a change in your state.
   Share this link: https://ujoin.co/campaigns/1453/actions/public

3. **Educate yourself:**
   If you would like to learn more about the bill language or other talking points about the proposed legislation visit the HCMA: https://4hcm.org/health-childhood-monitoring-act/



Hypertrophic Cardiomyopathy Association
Serving the HCM Spectrum Disorder Community Since 1996

GETTING STARTED THE HCM JOURNEY PROGRAMS

Draft language for consideration: State-specific modification may be required

Healthy Cardiac Monitoring Act

AN ACT concerning the cardiac health of children and student athletes.

BE IT ENACTED *by the Senate and General Assembly:*

- **Short title.**
  1. This act shall be known and may be cited as the "**Healthy Cardiac Monitoring Act**"
- **Annual physical examination of child, questions relative to cardiac health required.**
  1. A registered, licensed, and certified health care professional defined as physician, advanced practice nurse, or physician assistant (MD, DO, PA, or APN/NP) who performs an annual physical examination of a child 19 years of age or younger shall include as part of that examination questions that evaluate a child's family history related to cardiac conditions contained in the "Preparticipation Physical Evaluation" (PPE) form developed jointly by the American Academy of Family Physicians, American Academy of Pediatrics, American College of Sports Medicine, American Medical Society for Sports Medicine, American Orthopaedic Society for Sports Medicine, and American Osteopathic Academy of Sports Medicine and the American Heart Association's 14 point screening for heart disease in the young.
     1. Questions regarding the following shall be added to the PPE above:
        1. The biologic heart health history of the child; including history of sperm/egg donor or biologic parent.
        2. Four specific questions to ask regarding biologic heart health history during cardiac screening in well-child visits and in PPE are (these questions are published in the policy statement by the American Academy of Pediatrics (AAP) in *Pediatrics* in June 2021 and in JAMA on Aug 18, 2021) :
           1. Have you ever fainted, passed out, or had an unexplained seizure suddenly and without warning, especially during exercise or in response to sudden loud noises, such as doorbells, alarm clocks, and ringing telephones?
           2. Have you ever had exercise related chest pain or shortness of breath?
           3. Has anyone in your immediate family (parents, grandparents, siblings) or other, more distant relatives (aunts, uncles, cousins) died of heart problems or had an unexpected sudden death before age 50? This would include unexpected drownings, unexplained auto crashes in which the relative was driving, or SIDS.
           4. Are you related to anyone with hypertrophic cardiomyopathy or hypertrophic obstructive cardiomyopathy, Marfan syndrome, arrhythmogenic cardiomyopathy, long QT syndrome, short QT syndrome, Brugada syndrome, or

There may be opportunities for you to visit your legislators in person. Understanding the bill and telling your personal story can make a difference.

Quick reference on why your representative should support legislation:

- This legislation seeks to improve the current health care system, improve discussion and evaluation for those who may benefit from an additional cardiac evaluation.
- Healthcare providers need assistance in helping parents understand the need to report family heart history.
- Many cardiac conditions have a genetic component and run in families, however, it is often overlooked in childhood examinations.
- Thousands of people living with undiagnosed heart conditions placing them at risk for complications including a sudden cardiac arrest at any age.

---

4. **Recruit others to help:**
   Do you know others in your community who are passionate about childhood wellness and cardiac health? Ask them to join you in training to support the *Healthy Cardiac Monitoring Act*. They can sign up here:

   Explaining to friends, family, or faith group why you are supporting this project:

   Those with HCM: I've got HCM, and the HCMA (who helps people understand my/our cardiac condition) is launching an effort to identify the undiagnosed thorough improving the "Well Child" screening, enhance student-athlete evaluations and educating health care providers and ensure families understand their own heart health history.

   Those without HCM: There are many different types of cardiac illness and too many people who go undiagnosed or misdiagnosed well into adulthood. I'm supporting establishing a law to help identify the undiagnosed thorough improving the "Well Child" screening, enhance student-athlete evaluations and educating health care providers and ensure families understand their own heart health history.

Many politicians use a built-in equation — when one person cares enough about an issue to send an email about it, that means there are at least 100 other people who feel the same way. If 50 people send emails, that represents 5,000 people. Politicians are keenly aware of this.

HCMA's Proposed Advocacy Bill – "Healthy Cardiac Monitoring Act"

Healthy Cardiac Monitoring Act

AN ACT concerning the cardiac health of children and student athletes.
BE IT ENACTED *by the Senate and General Assembly:*

1. **Short title.**
    a. This act shall be known and may be cited as the "**Healthy Cardiac Monitoring Act**"
2. **Annual physical examination of child, questions relative to cardiac health required.**

a. A registered, licensed, and certified health care professional defined as physician, advanced practice nurse, or physician assistant (MD, DO, PA, or APN/NP) who performs an annual physical examination of a child 19 years of age or younger shall include as part of that examination questions that evaluate a child's family history related to cardiac conditions contained in the "Preparticipation Physical Evaluation" (PPE) form developed jointly by the American Academy of Family Physicians, American Academy of Pediatrics, American College of Sports Medicine, American Medical Society for Sports Medicine, American Orthopaedic Society for Sports Medicine, and American Osteopathic Academy of Sports Medicine and the American Heart Association's 14 point screening for heart disease in the young.

i. Questions regarding the following shall be added to the PPE above:

1. The biologic heart health history of the child; including history of sperm/egg donor or biologic parent.
2. Four specific questions to ask regarding biologic heart health history during cardiac screening in well-child visits and in PPE are (these questions are published in the policy statement by the American Academy of Pediatrics (AAP) in *Pediatrics* in June 2021 and in JAMA on Aug 18, 2021) :

a. Have you ever fainted, passed out, or had an unexplained seizure suddenly and without warning, especially during exercise or in response to sudden loud noises, such as doorbells, alarm clocks, and ringing telephones?
b. Have you ever had exercise related chest pain or shortness of breath?
c. Has anyone in your immediate family (parents, grandparents, siblings) or other, more distant relatives (aunts, uncles, cousins) died of heart problems or had an unexpected sudden death before age 50? This would include unexpected drownings, unexplained auto crashes in which the relative was driving, or SIDS.
d. Are you related to anyone with hypertrophic cardiomyopathy or hypertrophic obstructive cardiomyopathy, Marfan syndrome, arrhythmogenic cardiomyopathy, long QT syndrome, short QT syndrome, Brugada syndrome, or catecholaminergic polymorphic ventricular tachycardia, Wolff-Parkinson-White syndrome or anyone younger than 50 years with a pacemaker or implantable defibrillator?

1. Preparticipation Physical Evaluation Form required for student athletes; certification statement.

a. The State Department of Education and the State Department of Health shall set forth guidance to both public and private schools and require that prior to the participation of any student

enrolled in grades -kindergarten to 12 on a school and/or community organization sponsored interscholastic or intramural athletic team or squad, the student shall have a physical examination using the "Preparticipation Physical Evaluation" form developed jointly by the American Academy of Family Physicians, American Academy of Pediatrics, American College of Sports Medicine, American Medical Society for Sports Medicine, American Orthopaedic Society for Sports Medicine, and American Osteopathic Academy of Sports Medicine and the American Heart Association's 14 point screening for heart disease in the young. The Preparticipation Physical Evaluation form shall include the History and Physical Examination components, and the additional questions required pursuant to section 2 subsection a. of this act. The Preparticipation Physical Evaluation form shall also include a certification statement, to be signed by the registered, licensed, and certified health care professional defined as physician, advanced practice nurse, or physician assistant (MD, DO, PA, or APN/NP) who performed the physical examination, attesting to the completion of the current professional development module established pursuant to subsection a. of section 4 of this act.

b. The State Department of Health shall create a single form to be utilized in all PPE's statewide.

c. The physical examination required by subsection a. of this section shall be conducted within 6 weeks to the first day of official practice in an athletic season and shall be conducted by a registered, licensed, and certified health care professional defined as physician, advanced practice nurse, or physician assistant (MD, DO, PA, or APN/NP) . All PPE must include the following features and be updated in accordance with the PPE Monograph developed jointly by the American Academy of Family Physicians, American Academy of Pediatrics, American College of Sports Medicine, American Medical Society for Sports Medicine, American Orthopaedic Society for Sports Medicine, and American Osteopathic Academy of Sports Medicine and the American Heart Association's 14 point screening for heart disease in the young.

i. (1) been advised by a registered, licensed, and certified health care professional defined as physician, advanced practice nurse, or physician assistant (MD, DO, PA, or APN/NP) not to participate in a sport;

ii. (2) sustained a concussion, been unconscious or lost memory from a blow to the head;

iii. (3) broken a bone or sprained, strained, or dislocated any muscles or joints;

iv. (4) fainted or blacked out;

v. (5) experienced chest pains, shortness of breath, or heart racing;

vi. (6) had a recent history of fatigue and unusual tiredness;

vii. (7) been hospitalized, visited an emergency room, or had a significant medical illness;

viii. (8) started or stopped taking any over the counter or prescribed medications; or

ix. (9) had a sudden death in the family, or whether any member of the student's family under the age of 50 has had a heart attack or heart trouble, and.

x. (10) asked specifically the new 4 questions listed in the subsection 2a.i.2 regarding the heart health history during cardiac screening in well-child visit and/or PPE.

b. A board of education of a public school district and the governing board or chief school administrator of a nonpublic school shall not permit a student enrolled in grades -kindergarten to 12 to participate on a school and/or community based organization sponsored interscholastic or intramural athletic team or squad unless the student has a completed a Preparticipation Physical Evaluation form and, if applicable, a completed health history update questionnaire as required by subsections a. and b. of this section.

1. Childhood Cardiac Screening (CCS) "[State name:] Childhood Cardiac Screening Professional Development Training" establishment.

a. The Commissioners of Education and Health shall establish a Childhood Cardiac Screening professional development module to increase the assessment skills of those health care practitioners who perform well-child physical examinations and screenings. For this purpose, the Commissioners of Education and Health shall either develop a module adhering to requirements in subsection b. of section 4 of this act, or adopt the module created by the New Jersey Commissioners of Education and Health in consultation with the New Jersey Chapter of the American Academy of Pediatrics, the New Jersey Academy of Family Physicians, the American Heart Association, and the New Jersey Chapter of the American College of Cardiology.

b. If the Commissioners of Education and Health choose to develop a new module they shall, in consultation with the state chapter of the American Academy of Pediatrics, the state chapter of the Academy of Family Physicians, the American Heart Association, and the state chapter of the American College of Cardiology, shall develop, by the (enter time here) school year, a Childhood Cardiac Screening professional development module to increase the assessment skills of those health care practitioners who perform well child physical examinations and screenings. The module shall include, but need not be limited to, the following:

i. (1) how to complete and review a detailed medical history with an emphasis on cardiovascular family history and personal reports of symptoms;
ii. (2) identifying symptoms of sudden cardiac arrest that may require follow up with a cardiologist;
iii. (3) recognizing normal structural changes of the athletic heart;
iv. (4) recognizing prodromal symptoms that precede sudden cardiac arrest;
v. (5) performing the cardiovascular physical examination;
vi. (6) reviewing the major etiologies of sudden unexplained cardiac death with an emphasis on structural abnormalities and acquired conditions; and
vii. (7) when to refer a student to a cardiologist for further assessment.

b. The module shall be posted on the websites of the Department of Education and the Dept of Health and links made available to the American Academy of Pediatrics, the (Enter Name of State Dept of health) Academy of Family Physicians, the American Heart Association, the American College of Cardiology, the Athletic Trainers' Society, the State Board of Medical Examiners, Board of Nursing, and the Society of Physician Assistants.

c. Data Collection:

i. Those completing the CCS will be kept in a database to ensure all providers have successfully completed the required modules. Data must be held for 10 years.
ii. An annual review containing the total number of exams completed and if a referral to cardiology was made must be maintained and reported annually to the state department of health.
iii. State department of health will report annually on the outcomes from this legislation and make the report available to the public on its website or by request in writing from the public.

1. Educational Pamphlet development and distribution plan.

a. The Commissioner of Education, in consultation with the Commissioner of Health, the American Heart Association, and the American Academy of Pediatrics, shall develop a pamphlet that provides information about the disease that can cause sudden cardiac arrest to children and their parents. The pamphlet shall include an explanation of sudden cardiac arrest, its incidence, a description of early warning signs, and an overview of the options that are privately available to screen for cardiac conditions that may lead to sudden cardiac arrest, including a statement about the limitations of these options.
b. The commissioner shall distribute the pamphlet, at no charge, to all school districts in the State. The commissioner shall update the pamphlet as necessary, and shall make additional copies available to nonpublic schools upon request.
c. In the 202_-202_ through the(TIME PERIOD) school years, each school district shall distribute the pamphlet to the parents or guardians of students participating in school sports.
d. In the (TIME PERIOD --) school year and in each subsequent school year, a school district shall distribute the pamphlet to each student and to their parents or guardians, as part of the student's preparticipation physical examination and completion of athletic permission forms. A student and their parent or guardian shall certify in writing that they received and reviewed the pamphlet.

1. Childhood Cardiac Screening professional development module; completion, retention and recertification.
a. A registered, licensed, and certified health care professional defined as physician, advanced practice nurse, or physician assistant (MD, DO, PA, or APN/NP) who performs annual physical examinations of children 19 years of age or younger, including examinations prior to the student's participation in a school and/or community based organization sponsored interscholastic or intramural athletic team or squad as required pursuant to subsection a. of section 3 of this act, shall complete a Childhood Cardiac Screening professional development module established pursuant to subsection a. of section 4 of this act and read the pamphlet developed pursuant to section 5 of this act every four years.
b. A contract between a school district and a school physician shall include a statement of assurance that the school physician has completed the Childhood Cardiac Screening professional development module established pursuant to section 4 of this act and has read the pamphlet developed pursuant to section 5 of this act within the past four years.
c. A registered, licensed, and certified health care professional defined as physician, advanced practice nurse, or physician assistant (MD, DO, PA, or APN/NP) who completes the Childhood Cardiac Screening professional development module as required pursuant to subsection a. of this section shall retain on file at that person's professional office a hard copy of the certificate of completion of the module. The hard copy of the certificate of completion of the module shall be made available upon request.
d. Upon every renewal of a certification, biennial registration, or renewal of a license by a health care professional defined as physician, advanced practice nurse, or physician assistant (MD, DO, PA, or APN/NP) who performs annual physical examinations of children 19 years of age or younger shall attest to the completion of the module within the past four years to the Board of Medical Examiners or the Board of Nursing, as appropriate. An application for renewal of a certification, biennial registration, or renewal of a license shall include a check box for attestation regarding compliance

with subsection a. of this section for a health care professional defined as physician, advanced practice nurse, or physician assistant (MD, DO, PA, or APN/NP) who performs annual physical examinations of children 19 years of age or younger or athletic pre-participation physical examinations.

e. Upon performing a pre-participation physical examination required by subsection a. of section 3 of this act, the physician, advanced practice nurse, or physician assistant shall sign the certification statement on the Preparticipation Physical Evaluation form required pursuant to subsection a. of section 3 of this act attesting to the completion of the module. The board of education of a public school district and the governing board or chief school administrator of a nonpublic school shall retain the original signed statement to attest to the qualification of the health care practitioner to perform the physical examination required by subsection a. of section 3 of this act.

1. Enforcement.

a. All registered, licensed, and certified health care professional defined as physician, advanced practice nurse, or physician assistant (MD, DO, PA, or APN/NP)referenced in this act, including those performing annual well-child physical examinations, pre-participation physical examinations, and school health practitioners, could be subject to a fine of starting at - $5000 and in addition fine of $1000 per child they examined if found not to have the certificate of completion for the Childhood Cardiac Screening module in their professional office or available upon request, as required by subsection c. of section 6 of this act.

b. All licensed health professionals referenced in this act who are found not to have completed the Childhood Cardiac Screening module established pursuant to subsection a. of section 4 of this act or read the Educational pamphlet developed pursuant to subsection a. of section 5 of this act within the past three years shall be subject to professional discipline, as determined appropriate by the practitioner's professional organization.

c. Registered, licensed and certified health care professional defined as physician, advanced practice nurse, or physician assistant (MD, DO, PA, or APN/NP) who falsely certify to having completed the Childhood Cardiac Screening module established pursuant to subsection a. of section 4 of this act or read the Sudden Cardiac Death pamphlet developed pursuant to subsection a. of section 5 of this act in any setting, including to their professional organizations, on contracts, on pre-participation forms, or in any other setting, may be prosecuted for a misdemeanor.

d. Medicaid shall not reimburse any registered, licensed, and certified health care professional defined as physician, advanced practice nurse, or physician assistant (MD, DO, PA, or APN/NP)for an annual well-child physical examination or an athletic pre-participation physical examination unless they have completed the Childhood Cardiac Screening module established pursuant to subsection a. of section 4 of this act and read the Sudden Cardiac Death pamphlet developed pursuant to subsection a. of section 5 of this act.

1. Regulations.

a. The Director of the Division of Consumer Affairs in the Department of Law and Public Safety and the State Board of Education, pursuant to the "Administrative Procedure Act" and in consultation with the Commissioner of Health, shall adopt rules and regulations to effectuate the purposes of this act.

b. [Left open for individual state regulatory language]

1. This act shall take effect on the first day of the fourth month next following the date of enactment, but the Director of the Division of Consumer Affairs, Commissioner of Health, and State Board of Education may take such anticipatory administrative action in advance thereof as shall be necessary for the implementation of this act.

STATEMENT:
The **Healthy Cardiac Monitoring Act** aims to ensure the cardiovascular health needs of all children are met, including those of student athletes in particular, and the training of registered, licensed, and certified health care professional defined as physician, advanced practice nurse, or physician assistant (MD, DO, PA, or APN/NP) to meet those needs.

First, it requires all registered, licensed, and certified health care professional defined as physician, advanced practice nurse, or physician assistant (MD, DO, PA, or APN/NP) who perform annual physical examinations of children 19 years of age or younger to evaluate childrens' cardiac health and family history using the "Preparticipation Physical Evaluation" form developed jointly by the American Academy of Family Physicians, American Academy of Pediatrics, American College of Sports Medicine, American Medical Society for Sports Medicine, American Orthopaedic Society for Sports Medicine, and American Osteopathic Academy of Sports Medicine and the American Heart Association's 14 point screening for heart disease in the young.

Second, it requires all schools to ensure that all students enrolled in grades kindergarten through twelve have a physical examination completed using the aforementioned "Preparticipation Physical Evaluation" form with specific additional questions regarding biologic heart health history during cardiac screening in well-child visits and in PPE before participation in any interscholastic or intramural athletic team. (source: published in the policy statement by the American Academy of Pediatrics (AAP) in *Pediatrics* in June 2021 and in JAMA on Aug 18, 2021).

Third, it requires the state to establish a Childhood Cardiac Screening professional development module, either a new module to be developed by the state, or the module already developed by the New Jersey Commissioners of Education and Health, New Jersey Chapter of the American Academy of Pediatrics, the New Jersey Academy of Family Physicians, the American Heart Association, and the New Jersey Chapter of the American College of Cardiology, or with alternative educational models that may be made available through public/private partnerships.

Fourth, it requires the development and distribution of a pamphlet that provides information about sudden cardiac arrest to children and their parents. The pamphlet shall include an explanation of sudden cardiac arrest, its incidence, a description of early warning signs, and an overview of the options that are privately available to screen for cardiac conditions that may lead to sudden cardiac arrest, including a statement about the limitations of these options, and shall be distributed at least once to all children during annual physical examination, and to all students and parents during pre-participation physical examinations.

Fifth, it requires all registered, licensed, and certified health care professional defined as physician, advanced practice nurse, or physician assistant (MD, DO, PA, or APN/NP) performing annual physical examinations of children, including athletic pre-participation physical examinations, as well as all school physicians, to complete the Childhood Cardiac Screening professional development module, retain their completion certificate, and read the sudden cardiac arrest informational pamphlet every four years. It requires all applications for renewal of practice certification for the aforementioned licensed health practitioners to include a check box attesting the practitioner has completed the Childhood Cardiac Screening professional development module and read the sudden cardiac arrest informational pamphlet within the past four years.

Finally, it establishes enforcement provisions for all sections of this act. These provisions include: a fine starting at $5000 for health practitioners plus $1000 per child exam without license bound by this law who are not able to produce the completion certificate for the Childhood Cardiac Screening professional development module, professional discipline for practitioners who have not completed the module or read the pamphlet within the past four years, possible prosecution for a misdemeanor of practitioners found to have falsely certified that they have completed the module and read the pamphlet, and, finally, lack of Medicaid reimbursement for annual well-child physical examinations and athletic pre-participation physical examinations provided by practitioners who have not completed the module and read the pamphlet.

Medical information for responding to Frequently Asked Questions & Answers (FAQs)

The Hypertrophic Cardiomyopathy Association's (HCMA) *Elizabeth T. McNamee Legislative Advocacy Committee* has compiled a comprehensive set of questions that you may encounter when communicating and meeting with lawmakers. These questions and answers provide you with medical information to educate lawmakers and inform them about the nuances of HCM, diseases in the HCM spectrum, and other genetic disorders associated with higher rates of cardiac arrest.

The HCMA has provided you with this information to review in advance, so you are prepared to deliver to-the-point clear messages during your communications with the lawmakers and their staff. The data is medically accurate, factual, and written to be efficiently provided by a person without a medical background.

We cannot emphasize enough the importance of preparation before meeting with the lawmaker or their staff. The best way to be confident in your discussions is to prepare yourself for questions that may come up. If you encounter any medical question, you have the information at your fingertips. Should you be faced with a question you do not know the answer to, reply, “I will check on that and get back to you,” that’s why the HCMA office is here to assist you. You can walk out of the meeting confident that you have delivered factual information that lawmakers needed and worked to build a trusting relationship as you made your “ask” regarding the "**H**ealthy **C**ardiac **M**onitoring **A**ct" (HCM Act).

Always remember, you are not alone on this advocacy journey. If you cannot find an answer to any of the questions you have encountered or if you want to gain more information about any of these topics, HCMA staff is there for you. You can always contact us via phone, web, and email. The HCMA's main office phone number is 973-983-7429, the web address is 4hcm.org, and the email to reach any of the staff is Support@4hcm.org. Please refer to the Contact Information provided for you at the beginning of the training module to reach out to the key contacts for this Legislative Advocacy Project.

Collectively we can bring about a change and improve the lives of young patients and their families affected by cardiomyopathies and other genetic cardiac conditions. We sincerely thank you in advance for becoming involved as a volunteer to advance these issues sponsored by the HCMA.

Frequently Asked Questions

Why do all children need screening?

Multiple conditions and risks can make children prone to sudden cardiac arrest (SCA) or sudden cardiac death (SCD) as well as other complications of heart disease. To date, the focus has mainly been only on screening student athletes. Given that the prevalence of all cardiac diseases, both genetic and congenital, thousands of children are living with undiagnosed cardiac disease.

Prevalence table:

Cardiac Health Spectrum of Diseases	Prevalence in General Population
Hypertrophic Cardiomyopathy (HCM)	1 in 200-500
Dilated Cardiomyopathy (DCM)	1 in 250-2,500
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	1 in 2,000-5,000
Marfan Syndrome	1 in 5,000 to 1.5 in 100,000
Long QT Syndrome (LQTS)	1 in 2,000
Brugada Syndrome (BrS)	1 in 2,000-10,000
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	1 in 5,000-10,000
Short QT Syndrome (SQTS)	1 in 1,000-5,000 in the adult population, and is about 1 in 2,000 in the pediatric population
Congenital Heart Disease (CHD)	6.90-10.25 in 1,000 in the general population, and is about 13.11 in 1,000 in the pediatric population
Early Repolarization Syndrome (ERS)	1-13 in 100
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1 in 100-1,000

The most common disorder for example: Hypertrophic Cardiomyopathy (HCM) is 1 in 250 many adults who have HCM are either not diagnosed, misdiagnosed, or live without symptoms, there are many unknown factors about the heart health history of parents. If a parent has HCM, the child has a 50% chance of having the genetic mutation for the disease. The only way to obtain the family heart health history and assess a child's risk for cardiac disease is to get Information during Well-Child Visits and in-school pre-participation screening.

The American Academy of Pediatrics identified four specific questions that PCP's should ask during the regular child visits to identify any risk of SCA or SCD. The following questions cover the entire spectrum of information needed for determining the cardiac health of a child:

1. Have you ever fainted, passed out, or had an unexplained seizure suddenly and without warning, especially during exercise or in response to sudden loud noises, such as doorbells, alarm clocks, and ringing telephones?
2. Have you ever had exercise-related chest pain or shortness of breath?
3. Has anyone in your immediate family (parents, grandparents, siblings) or other, more distant relatives (aunts, uncles, cousins) died of heart problems or had an unexpected sudden death before age 50? This would include unexpected drownings, unexplained auto accidents in which the relative was driving, or SIDS.

4. Are you related to anyone with hypertrophic cardiomyopathy, hypertrophic obstructive cardiomyopathy, Marfan syndrome, catecholaminergic polymorphic ventricular tachycardia, Wolff-Parkinson-White syndrome, or anyone younger than 50 years with a pacemaker or implantable defibrillator?

Source: Erickson, Christopher C., MD, FAAP, et al., PEDIATRICS (from the American Academy of Pediatrics), "Sudden Death in the Young: Information for the Primary Care Provider," Volume 148, number 1, July 2021;
https://www.mayoclinic.org/diseases-conditions/hypertrophic-cardiomyopathy/symptoms-causes/syc-20350198

Why do we screen student athletes?

We screen student athletes to identify those at-risk for sudden cardiac arrest (SCA) or sudden cardiac death (SCD) during sports participation.

The role of the primary care provider is critical in the evaluation of children, especially in middle school or junior high. These healthcare providers generally manage children from infancy into teenage years or young adulthood. They often have a long relationship with the child, the family, and the community. Primary care physicians (PCPs) generally are the ones involved with school pre-participation screening.

The best time to screen student-athletes for cardiac health is during the pre-participation screening. By asking questions about the heart health history of the child, including the history of a sperm/egg donor or birth parents if the child is adopted, PCPs gather the family history. The American Academy of Pediatrics published a policy statement in July 2021, asking PCPs to ask an additional four questions explicitly targeting the biologic heart health history during cardiac screening in well-child visits and pre-participation screening.
Source: Erickson, Christopher C., MD, FAAP, et al., PEDIATRICS (from the American Academy of Pediatrics), "Sudden Death in the Young: Information for the Primary Care Provider," Volume 148, number 1, July 2021

What happens if the screen is positive?

If the Well-Child Visit or the school pre-participation screening leads to positive results, the primary care provider should immediately refer the child to a pediatric cardiologist or electrophysiologist. Before evaluation by the specialists, the PCP, as a precaution, should hold the child back from any athletic participation and may recommend restricting some other activities. Once the specialists complete a detailed cardiovascular evaluation, they will provide more instructions on the child's safe activity level.
Source: Erickson, Christopher C., MD, FAAP, et al., PEDIATRICS (from the American Academy of Pediatrics), "Sudden Death in the Young: Information for the Primary Care Provider," Volume 148, number 1, July 2021

Why do we need the "Healthy Cardiac Monitoring Act" (HCM Act)?

The **Healthy Cardiac Monitoring Act** aims to ensure that the cardiovascular health needs of all children are met, including those of student athletes, through the training of registered, licensed health care professionals. Certified health care professionals are defined as physicians, advanced practice nurses, or physician assistants (MD, DO, PA, or APN/NP. This Act ensures all children receive cardiac screening during Well-Child Visits and school pre-participation screenings. The Act serves the following purposes:

1. Requires all healthcare providers mentioned above to perform an annual examination of children 19 years of age and younger to evaluate their cardiac health and family history using the "pre-participation physical evaluation" form, including the four new questions for screening for heart disease in the young.

2. It requires all schools to ensure that every student enrolled in grades kindergarten through twelve have a physical examination completed using the aforementioned "Pre-participation Physical Evaluation" form with specific additional questions regarding biologic heart health history during cardiac screening in well-child visits and PPE before participation on any interscholastic or intramural athletic team.

3. It requires the state to establish a Childhood Cardiac Screening professional development module, either a new module to be developed by the state or the module already developed by the New Jersey Commissioners of Education and Health, New Jersey Chapter of the American Academy of Pediatrics, the New Jersey Academy of Family Physicians, the American Heart Association, and the New Jersey Chapter of the American College of Cardiology, or with alternative educational models that may be made available through public/private partnerships.

4. It requires developing and distributing a pamphlet that gives information about sudden cardiac arrest to children and parents. The pamphlet must include an explanation of sudden cardiac arrest, its incidence, early warning signs, an overview of the options that are available to screen for cardiac conditions that may lead to sudden cardiac arrest (including the limitations of these options) and shall be distributed at least once to all children during annual physical examination, and to all students and parents during pre-participation physical exams.

5. It requires all registered, licensed, and certified health care professionals performing annual physical examinations of children, including athletic pre-participation physical examinations, as well as all school physicians, to complete the Childhood Cardiac Screening professional development module, retain their completion certificate, and read the sudden cardiac arrest informational pamphlet every four years. It requires all applications for renewal of practice certification for the aforementioned licensed health practitioners to include a check box attesting the practitioner has completed the Childhood Cardiac Screening professional development module and read the sudden

cardiac arrest informational pamphlet within the past four years.

6. It establishes enforcement provisions for all sections of this act.

How will this screening be enforced?

The "**H**ealthy **C**ardiac **M**onitoring **A**ct" (HCM Act) establishes financial and disciplinary enforcement provisions for all sections of this act. These provisions include:

a. A fine starting at $5000 for health practitioners bound by this law plus $1000 per child exam without a license if they cannot produce the completion certificate for the Childhood Cardiac Screening professional development module.

b. Professional discipline for practitioners who have not completed the module or read the pamphlet within the past four years.

c. Possible prosecution for a misdemeanor of practitioners found to have falsely certified that they have completed the module and read the pamphlet.

d. Lack of Medicaid reimbursement for annual well-child physical examinations and athletic pre-participation physical examinations provided by practitioners who have not completed the module and read the pamphlet.

*Source: Hypertrophic Cardiomyopathy Association (HCMA), Elizabeth T. McNamee Legislative Advocacy Committee, "**H**ealthy **C**ardiac **M**onitoring **A**ct" (HCM Act)*

Have any other States passed this bill? What was their experience?

New Jersey (NJ) is the only state in the United States with a comprehensive bill similar to the one being proposed in all the other states. The existing bill in NJ requires updates. To view information on New Jersey's existing bill, click on the links below.

https://www.nj.gov/education/students/safety/health/services/PDModule.shtml

https://www.njleg.state.nj.us/2012/Bills/AL13/71_.PDF

https://www.njleg.state.nj.us/bills/BillView.asp

How much will it cost to screen student-athletes?

No new costs are anticipated to screen student-athletes. Currently, all states implement some form of "Well Child Visits" and "Pre-participation Physical Evaluation" screenings. These screenings are a requirement. Including additional questions to evaluate the cardiac health of the children is not expected to add any new costs. If risk of cardiac disease is present, referrals for cardiac evaluations are part of routine healthcare and covered by insurance.

What are the costs and logistics of implementing this bill (including the educational component and medical tests)?

The Hypertrophic Cardiomyopathy Association (HCMA) will be working with the states to identify their needs for implementing this bill. The costs are expected to be nominal.

Given the focused effort of the American Academy of Pediatrics for effectively screening the children and through additional private and public partnerships and grants from sponsors, the HCMA believes that the proposed bill will be implemented in each State.

What inherited diseases should we screen children for and why?

Prevalence: “Prevalence is the proportion of a population who have a specific characteristic in a given time period” How many people have this disease out of a certain number?

Inherited diseases run in the family. With careful screening during well-child doctor’s visits, including asking questions about family history, the following diseases are more likely to be found early and treated to reduce the impact on quality of life and even death. Sudden cardiac arrest can be prevented with the placement of an ICD in those at risk.

- **Hypertrophic cardiomyopathy (HCM)** has a prevalence of about 1 in 250* people in the general population.
- **Dilated cardiomyopathy (DCM)** has a prevalence that ranges from 1 in 250 to 1 in 2,500 people in the general population.
- **Arrhythmogenic right ventricular cardiomyopathy (ARVC)** has a prevalence that ranges from 1 in 2,000 to 1 in 5,000 in the general population.
- **Marfan Syndrome (MFS)** has a prevalence that ranges from 1 in 5,000 to 1.5 in 100,000 in the general population.
    - For reference, the prevalence of multiple sclerosis ranges from about 8-150 in 100,000 people in the general population.
- **Long QT syndrome (LQTS)** has a prevalence of about 1 in 2,000* people in the general population.
- The prevalence of **Brugada Syndrome** ranges from 1 in 2,000 to 1 in 10,000 people in the general population.
- The prevalence of **catecholaminergic polymorphic ventricular tachycardia (CPVT)** ranges from 1 in 5,000 to 1 in 10,000 in the general population.
- The prevalence of **short QT syndrome (SQTS)** is about 1 in 2,000 in the pediatric population.

- The prevalence of **congenital heart disease (CHD)** is about 13.11 in 1,000 in the pediatric population.
    - For reference, the prevalence of cerebral palsy ranges from 1.5-3 in 1,000 people in the general population.

- The prevalence of **early repolarization syndrome (ERS)** ranges from 1-13 in 100 people in the general population.

- The prevalence of **anomalous aortic origin of coronary arteries (AAOCA)** ranges from 1 in 100 to 1 in 1,000 in the general population.

*For diseases with prevalences that are still being optimized, estimates have been provided. You can find documents supporting these estimates in the "Prevalence Document."

What is Cardiomyopathy?

Cardiomyopathy represents a collection of diverse conditions of the heart muscle. These diseases have many causes, symptoms, and treatments and can affect people of all ages and races.

When cardiomyopathy occurs, the normal muscle in the heart can thicken, stiffen, thin out, or fill with substances the body produces that do not belong in the heart muscle. As a result, the heart muscle's ability to pump blood is reduced, which can lead to irregular heartbeats, the backup of blood into the lungs or the rest of the body, and heart failure.

Cardiomyopathy can be acquired—developed because of another disease, condition, or factor—or inherited. The cause isn't always known.

The main types of cardiomyopathy include the following:

- **Dilated (DCM):** - thin walls that do not pump well - where one of the pumping chambers (ventricles) of the heart is enlarged. This is more common in males and is the most common form of cardiomyopathy in children. It can occur at any age and may or may not be inherited.
- **Hypertrophic (HCM):** where the heart muscle is thickened. It can be "non-obstructed" or "obstructed" (referred to as Hypertrophic Obstructive Cardiomyopathy (HOCM)). This often presents in childhood or early adulthood and can cause sudden death in adolescents and young adult athletes. It is usually an inherited condition, and a person may not have any symptoms. If there is a family history of this, other family members can be tested and adjust their activities to reduce the risk of sudden death.
- **Arrhythmogenic (ARVC):** the disease causes irregular heartbeats or rhythms. It is due to fatty fibrosis in the right ventricle. This is often inherited and is more common in males.
- **Restrictive:** where the heart muscle is stiff or scarred, or both. It can occur with amyloidosis or hemochromatosis, and other conditions. This is the least common type.

Source: https://www.cdc.gov/heartdisease/cardiomyopathy.htm and https://4hcm.org/hcm-prevalence/?fl_builder

How common is cardiomyopathy? HCM? (Prevalence of HCM)

We are focused on HCM, not just because we are the HCMA, but because it is the most common cardiomyopathy and is often the cause of sudden death in young athletes. Learn more here:

https://www.cdc.gov/heartdisease/cardiomyopathy.htm and
https://4hcm.org/hcm-prevalence/?fl_builder

What is Hypertrophic Cardiomyopathy (HCM)?

Learn more here:

Source: https://4hcm.org/hcm-development/

When is Hypertrophic Cardiomyopathy (HCM) diagnosed?

Children and adolescents with HCM usually come to attention when:

- A family screening is performed after an adult in the family is found to be affected.
- A doctor observes a heart murmur, and a cardiologist evaluates the patient.
- An abnormal ECG/EKG is found before a medical procedure.
- The person appears to have athletically induced asthma and is given more advanced screening.

The average age of diagnosis within the HCMA database is 40 years. However, the disease may have been present for many years and defied diagnosis. With pediatricians required by law to perform a standard screening for inherited cardiac diseases, many people would be diagnosed early and be able to lead healthier lives.

Source: https://4hcm.org/hcm-development/ Please note there are other references to other scientific journals on this page at the HCMA site.

How many people die of hypertrophic cardiomyopathy per year? How many die from cardiac causes the HCM Act hopes to reach in time?

Based on data collected through the Center for Disease Control and Prevention in 2018 in the United States, 1,801 people died with HCM as a primary cause of death, 107 were under the age of 24 years. Dilated cardiomyopathy accounted for over 41,000+ deaths in all ages with 600+ in those 1 day to 24 years.

Each year nearly 2,000 children and young adults under the age of 24 die from cardiac diseases.

Source: https://4hcm.org/hcm-complications/

What are the long-term risks and possible complications in HCM which can cause death?

The common complications in HCM which could cause death are the following:

- ***Arrhythmias*** - irregularities of the heartbeat.
- ***Sudden cardiac arrest –*** as its name applies, sudden cardiac arrest can occur with little or no warning and can occur at any age. The current estimate is that the risk of sudden cardiac arrest is between 1 and 2% per year in the HCM population.
- ***Heart Failure*** **-** means that blood is not coming from the heart fast enough to meet the body's needs. There are two general ways this can happen: the heart may not pump hard enough, or it may not fill well enough. Problems with pumping (systolic heart failure) are probably more common in the populace as a whole, but difficulties with filling (diastolic heart failure) are much more common among HCM patients.
- ***"Burnt out" or "End Stage" HCM*** **-** most HCM patients never experience this part of the disease. Presently it appears that about 3% of all HCM patients get to this point. We do not really understand why some people reach end-stage HCM.
- ***Heart Block*** **-** The normal electrical signal may travel down to the ventricles slowly or may be partly or completely blocked. These are all called heart block. Certain kinds of heart block (left or right bundle branch block) are harmless by themselves, but some other types require a pacemaker.
- ***Endocarditis*** **-** Endocarditis is an infection of the heart which occurs rarely in hypertrophic cardiomyopathy. Bacteria in the bloodstream can attach to the inside of the heart, mainly because blood flow in HCM hearts is often turbulent.

Source: https://4hcm.org/hcm-complications/

What are "enlarged heart" and "athlete's heart" -- are they the same as HCM?

They are not the same. For decades there was significant confusion between "athletes heart" and HCM.

An enlarged heart (cardiomegaly) isn't a disease but rather a sign of another condition. An enlarged heart may result from short-term stress on the body, such as pregnancy, or a medical condition, such as weakening the heart muscle, coronary artery disease, heart valve problems, or abnormal heart rhythms. Certain conditions may cause the heart muscle to become thicker or cause one of the heart's chambers to dilate, making the heart larger. Depending on the condition, an enlarged heart may be permanent (e.g., HCM) or temporary (e.g., Athlete's Heart.)
The diagnosis of "athlete's heart" is actually very rare and typically associated with high-intensity competitive endurance athletic participation (cycling, cross-country skiing, rowing). While both

enlarged heart and athlete's heart can cause the heart to thicken, "athlete's heart" is typically one with a normal ECG/EKG and will revert to normal measurement when high-intensity exercise is discontinued.

Source:
https://www.mayoclinic.org/diseases-conditions/enlarged-heart/symptoms-causes/syc-20355436;
https://4hcm.org/hcm-diagnosed/

What are the symptoms of Hypertrophic Cardiomyopathy (HCM)?

There is no particular symptom or complaint unique to hypertrophic cardiomyopathy, but patients typically experience certain symptoms.

What causes symptoms in HCM? This is a process of the heart's inability to pump and relax effectively. As HCM can be present for years before diagnosis, symptoms do not usually begin suddenly. Symptoms often increase slowly, so the person thinks they are normal.

It is essential to understand that some patients may never have recognizable symptoms yet still be at high risk for HCM related complications, including sudden cardiac arrest. This is why screening, including a detailed family history, is so essential for catching inherited cardiac diseases early.

Symptoms for HCM and many other cardiac diseases include the following:

- Shortness of breath
- Palpitations
- Chest Pain/Pressure
- Fatigue
- Light-headedness
- Brain Fog
- Fainting (syncope) and near-syncope
- Muscle pains
- No Symptoms

If you want to learn more about symptoms, please refer to the HCMA website: https://4hcm.org/symptom-journey/.

How do you detect Hypertrophic Cardiomyopathy (HCM)?

For some, the path to diagnosis can be simple, highly complicated, confusing, and time-consuming for many.

All newly diagnosed HCM patients need some or all of these tests, including ECG, echocardiogram, stress echocardiogram, event/Holter Monitoring, genetic testing, and cardiac MRI. Some patients may need additional testing, including cardiac catheterization, transesophageal echocardiogram, implantable loop recorder, and other tests.

For more information on diagnosing HCM and other cardiac conditions, please see https://4hcm.org/diagnostic-journey/.

What Diagnostic Tools are used to detect inherited cardiac diseases?

There are a variety of diagnostic tools used to detect cardiac diseases. Click the test name for more information.

- Echocardiogram, Transthoracic (TTE)
- EKG/ECG - electrocardiogram
- Event Monitor
- Holter Monitor
- MRI
- Genetic Testing
- Cardiac Catheterization
- Stress Test or Stress Echocardiogram (sometimes cardiopulmonary exercise test)
- Transesophageal Echocardiogram (TEE)
- Implantable Loop Recorder
- EP Testing
- Tilt Table
- PET Scan
- Cardiac Biopsy

What is "Heart Murmur"?

During a physical exam, the doctor uses a stethoscope to listen to the heart at different places on your chest to hear the sounds your heart valves make as blood travels through them.

Typically, the heartbeat has two sounds – "lub dub." The first sound, "lub," is heard as the mitral and tricuspid valves close. The second sound, "dub," is the aortic and pulmonic valves snapping shut.

A **heart murmur** is a swishing sound heard when there is turbulent or abnormal blood flow across a heart valve. Possible causes of heart murmurs include valvular heart disease, hypertrophic cardiomyopathy, or septal defects. Anemia and Hyperthyroidism can also cause heart murmurs.

Regular physical exams can detect any abnormal heart sounds. If a murmur is heard, further evaluation by your physician will be required to determine the reasons behind the murmur and the severity of the problem.
Sources: https://my.clevelandclinic.org/health/diseases/17083-heart-murmur

Why are some HCM patients told they have asthma?

Some HCM patients might be accurately diagnosed and have asthma. However, those with HCM often report symptoms that are misclassified as non-cardiac. One of these misdiagnoses is asthma. In a survey conducted by the HCMA, 19% report they were advised that various forms of asthma were to blame for their shortness of breath.

As with asthma, other HCM symptoms could be misclassified as other conditions. According to the survey conducted by HCMA, 17% reported being diagnosed with anxiety or panic attacks when reporting feelings of their heart racing. 18% reported a diagnosis of depression when explaining they lacked energy or wanting to participate in social events, and 51% were told their abnormal heart sounds were simply an "innocent murmur."

Proper diagnosis and appropriate treatments are critical for managing HCM symptoms.
Sources: https://4hcm.org/hcm-diagnosed/

How is HCM treated?

There are many HCM treatment options. Each patient with their cardiologist needs to evaluate which treatment options they may consider given what is in their best interest both in the short-term and long-term before engaging in treatment for HCM. Best outcomes come when a patient engages with a cardiologist who specializes in the evidence-based treatment of HCM. In that case, the HCMA strongly encourages to go to one of the HCMA Recognized Center of Excellence Programs that handle high-volume procedures and are equipped to handle any adverse event. Not every Center of Excellence cares for pediatric patients, so look at the directory before you call.

Treatment options can be categorized into three groups: (1) Medication Therapy, (2) Surgery or other procedures, and (3) Rhythm Management Devices. This list of options is limited to those used in children. For other options offered to adults, please visit the HCMA website. Click the name of the therapy for more information.

Medication Therapy	Surgery or other Procedures	Rhythm Management Devices
Beta-Blockers	Myectomy	Transvenous Implantable Cardioverter Defibrillator (ICD) Traditional
Calcium Channel Blockers	Valve Repair	
Diuretics	Valve Replacement	
Antiarrhythmics	Pulmonary Vein Ablation	Subcutaneous Implantable Cardioverter Defibrillator (ICD)
Blood Thinners	Catheter Ablation for Arrhythmias	
Antibiotics	Heart Transplant	Device Replacement
Sodium Channel Blockers		Pacemaker
		Lead Extraction

How does cardiomyopathy affect patients' lives?

All symptoms and challenges identified with cardiomyopathies do not exist for all patients every day, and they are not the same for every patient. The burden of cardiac disease is real for every patient. Managing the disease is an ongoing reality for most patients that requires frequent lifestyle, career, and financial adjustments.

The most troubling symptoms that require constant adjustments in daily life are;

- Shortness of breath
- Exercise intolerance including difficulty keeping up with other children
- Arrhythmias and Palpitations which lead to increased anxiety and worry
- Chest pain which manifests itself differently for each patient
- Chronic and Acute Fatigue which fluctuates with changing temperatures, during exertion, and when patients experience dehydration. Fatigue pushes patients to withdraw from many social and daily activities as they must conserve energy for more critical functions of daily living.
- Brain fog, which is momentary lapses in mental acuity and alertness, is very common. Some of this is due to the side effects of the medications used in treatment.
- Sudden Cardiac Arrest is the most concerning complication of HCM and other cardiac diseases, and if a person has many of the risk factors, they live with the fear daily. Having an ICD implanted can give peace of mind but comes with the worry they might be shocked.
- The discomfort of feeling ill and living with the burden of disease takes a toll on cardiac patients and causes emotional distress and depression.

  These key points can summarize the overall impact of HCM on daily living:

  1. ***The fear of a lifetime of uncertainty*** - In "The Voice of the Patient Report for HCM," developed and published by the HCMA for the FDA, patients spoke about their frustrations and disappointments at not being able to hold a job, tend to their children, or complete simple tasks such as bathing, cooking, and dressing. Along with the uncertainty is the angst of not knowing whether the immediate change in function is short-lived or a serious progression that will require additional testing, medications, and treatments.
  2. ***The frustration of being misdiagnosed and misunderstood*** - Many HCM patients first had symptoms when little was known about the condition and spent years with inappropriate medications, incomplete diagnoses, and worries about their physical capabilities. Even today, patients are primarily treated according to their symptoms -- asthma, panic attacks, sleep disorders, vasovagal syncope, migraines, thyroid disorders, etc. – instead of being evaluated for an underlying cause. The lack of medical knowledge about the condition is a genuine concern of patients, especially those needing emergency care. Some patients find themselves educating the emergency room staff to

avoid confusion, unnecessary testing, and potentially dangerous drug interactions. In addition, many feel they are "misunderstood" because they "don't look like a patient" or "can be fine one day and not the next." Parents worry that this will also be a problem for their children.

3. ***The strain on relationships*.** The fear of lifetime uncertainty adds additional stress to the patients and impacts their marital, parental, employment, and other social relationships. Stories of divorce, anxiety, separation, and periods of isolation were common. Knowing there is no cure for the disease, patients, especially those diagnosed at a young age, face a lifetime of daily decisions about whether it will be a "good day or a bad day."

The burden of HCM" is high, and its impact on daily life requires constant adjustments.

Source:
https://4hcm.org/wp-content/uploads/2021/06/Voice-of-the-HCM-patient-Report-final-January-9-2021.pdf

Why is it important to know that you have a pre-existing heart condition?

With the onset of the Covid-19 pandemic, understanding what pre-existing conditions may present in a person or family has become more critical than ever. Through our healthcare providers and public health officials, we have all learned that pre-existing conditions such as cardiomyopathy may cause severe complications when impacted by Covid-19 and other easily transmissible illnesses.

Being an educated patient or a caregiver, knowing your family health history, working jointly with your healthcare provider, and taking the necessary precautions to avoid contracting any additional illnesses will help you lead as normal a life as possible and prevent unnecessary complications.
Source: https://4hcm.org/hcm-the-disease-3/

If a parent has HCM, what is the chance that their child will get HCM?

Hypertrophic Cardiomyopathy (HCM) is usually passed down through families, and it is an inherited disease. If a parent has HCM, the offspring has a 50% chance of having the genetic mutation for the disease.
Source: https://4hcm.org/how-to-screen-family-for-hcm/;
https://www.mayoclinic.org/diseases-conditions/hypertrophic-cardiomyopathy/symptoms-causes/syc-20350198

How do you screen family members of people diagnosed with HCM and other genetic heart diseases?

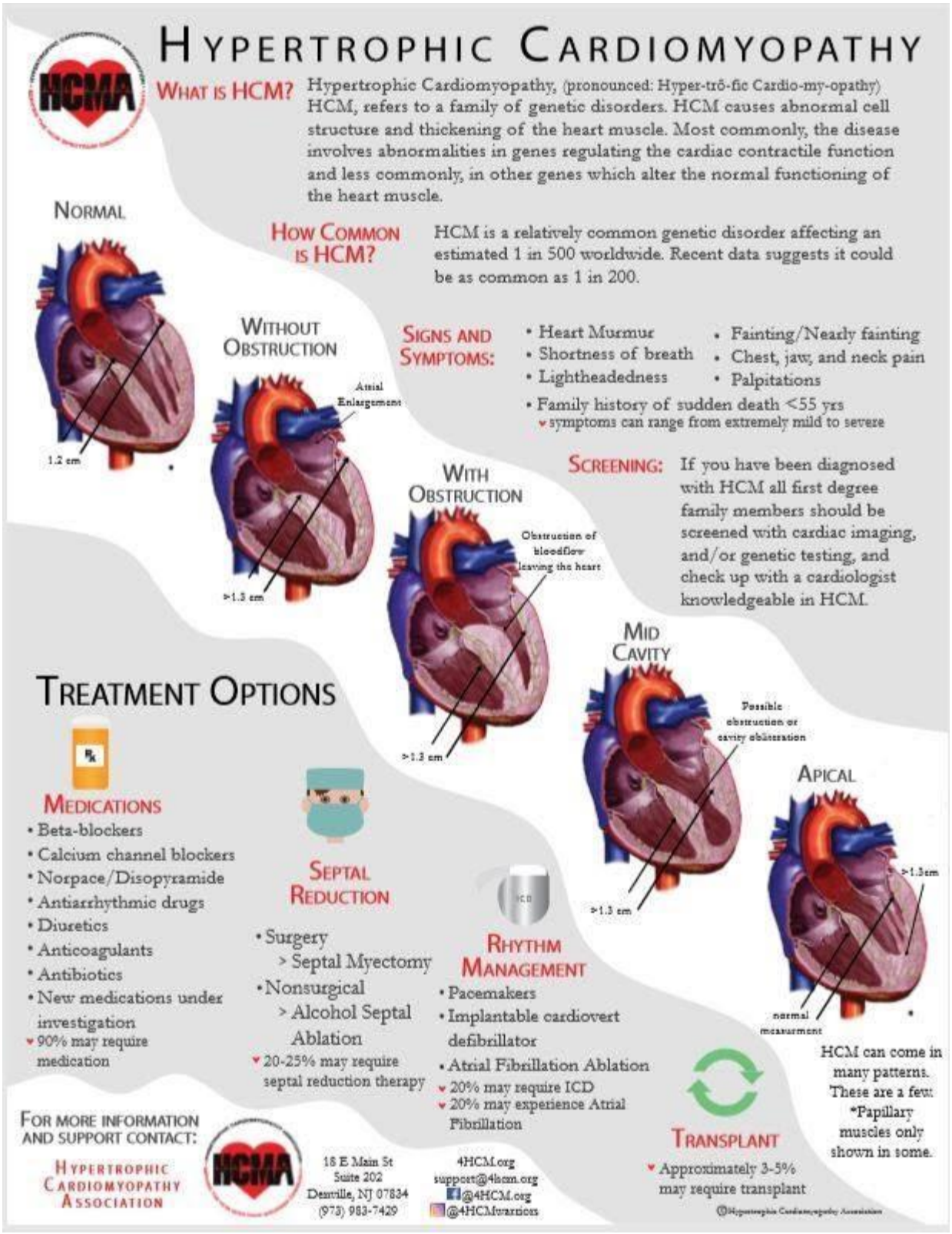
Parents, children, or siblings of a person with an inherited heart disease should be screened for the disease. ***All first-degree blood relatives should be screened***.

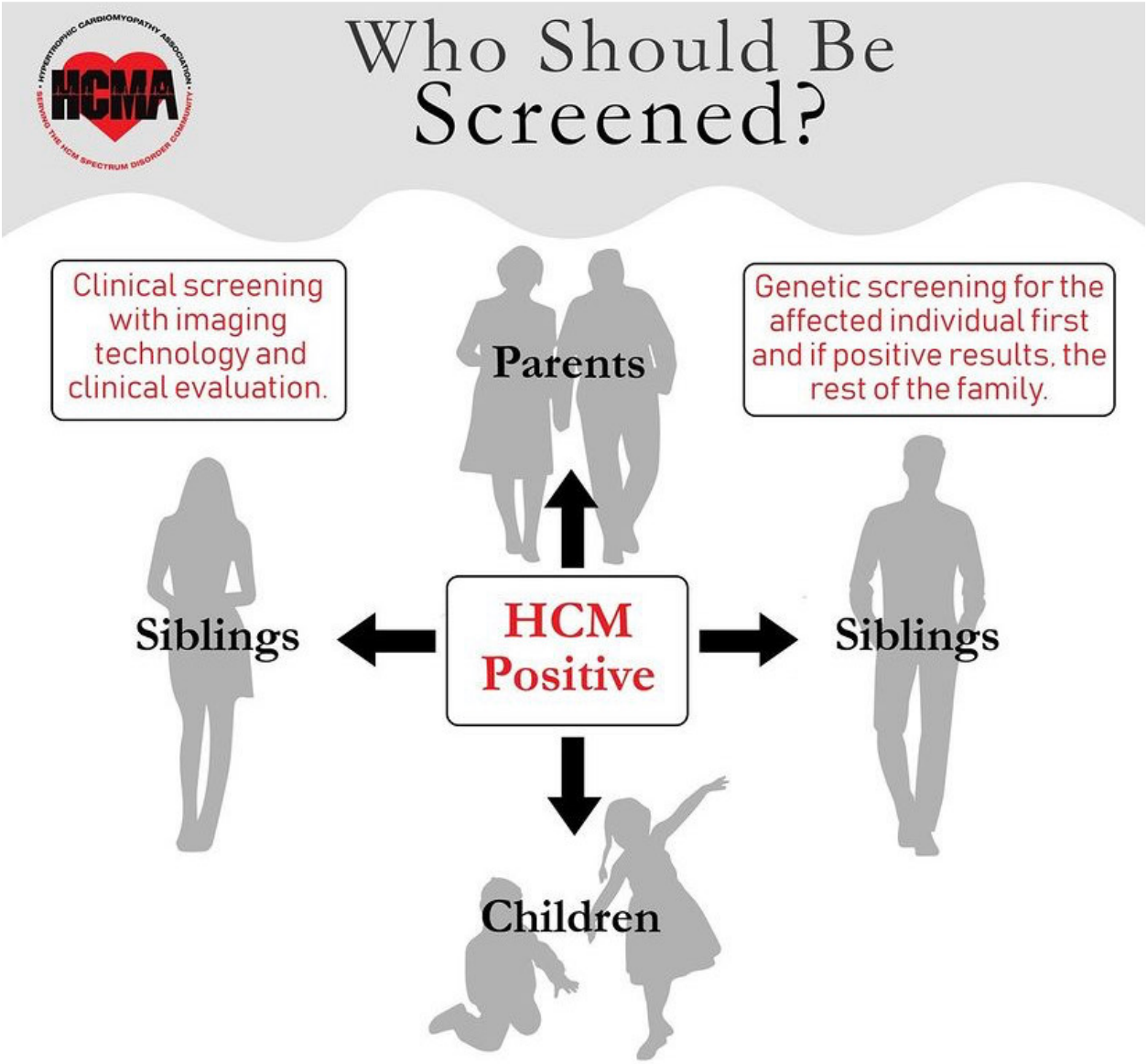
If you are diagnosed with HCM, your parents, siblings, and children should all be screened. Think of your family tree - you will want to ensure that those UP (parents), OVER (siblings), and DOWN (children) are all encouraged to be screened. Other family members found to have HCM should then go up, over, and down to ensure all those at risk are found.

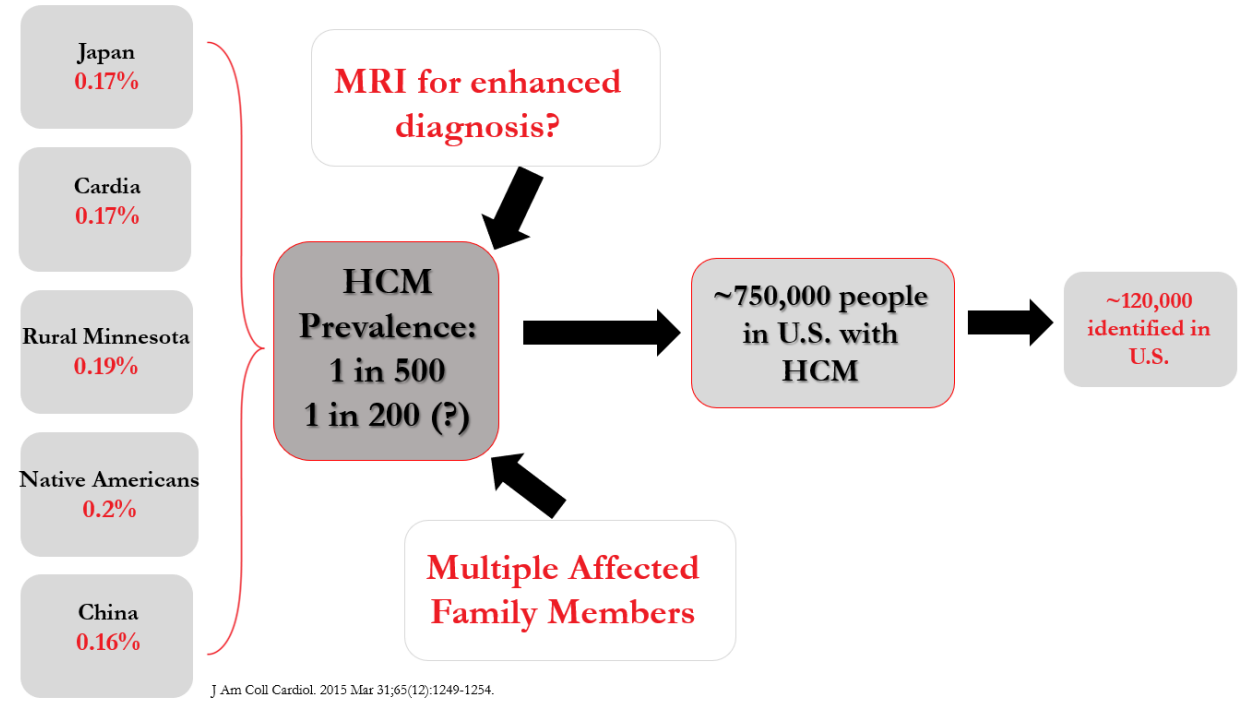
This screening MUST include EKG/ECG, Echocardiogram, and a cardiac check-up by a cardiologist. Ideally, the cardiologist should have specialized knowledge of Hypertrophic Cardiomyopathy, and the imaging screening is done at a high-quality imaging service center.

The screenings must be done annually from the onset of puberty, approximately age 12, to full growth (age 20-25). For ages 25 and over, screenings must be done every 3-5 years. If there is a known genetic basis for the disease in the family, those who have a negative genetic test can forgo the annual screenings.
Source: *https://4hcm.org/how-to-screen-family-for-hcm/*

LEAVE-BEHIND RESOURCES







J Am Coll Cardiol. 2015 Mar 31;65(12):1249-1254.

State Demographics & Prevalence Data

California State Demographics and Prevalence Data

Table 1: California (CA) State Demographics

Total State Population[1]	39,368,078
Number of Senators[2]	40
Population per Senator[3]	984,202
Number of Assembly Members[4]	80
Population per Assembly Member[5]	492,101
Pediatric Population Percentages (%) (<18 years of age)[6]	22.3
Pediatric Population Calculated (<18 years of age)[7]	8,779,081

Source:

[1]Population Data - SC-EST2020-18+POP-RES: Estimates of the Total Resident Population and Resident Population Age 18 Years and Older for the United States, States, the District of Columbia, and Puerto Rico: July 1, 2020. U.S. Census Bureau, Population Division; Release Date: December 2020, Updated May 2021 with Puerto Rico Estimates

[2] https://ballotpedia.org/California_state_legislative_districts#Senate

[3] Population per Senator is a calculated number. The formula used is (Total State Population/Number of Senators)

[4] https://ballotpedia.org/California_state_legislative_districts#House

[5] Population per Assembly Member is a calculated number. The formula used is (Total State Population/Number of Assembly Members)

[6] SC-EST2020-18+POP-RES

[7] Pediatric Population is calculated number. The formula used is (Pediatric Population Percentages provided in the SC-EST2020-18+POP-RES file multiplied by the State Population).

Table 2: Cardiac Health - Spectrum of Diseases - Prevalence in USA

Disease Type	PREVALENCE RANGES	
	Adult & Pediatric Patients (High End of the Range)	Adult & Pediatric Patients (Low End of the Range)
Hypertrophic Cardiomyopathy (HCM)	0.50%	0.20%
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	0.05%	0.02%
Dilated Cardiomyopathy (DCM)	0.40%	0.04%
Marfan Syndrome	0.02%	0.00%
Early Repolarization Syndrome (ERS)	13.00%	1.00%
Long QT Syndrome (LQTS)	0.05%	No data available
Short QT Syndrome (SQTS)	0.10%	0.02%
Brugada Syndrome (BrS)	0.05%	0.01%
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	0.02%	0.01%
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1.00%	0.10%
Congenital Heart Disease (CHD)	1.03%	0.69%

Source: Cardiac Health - Spectrum of Diseases Prevalence Data & Sources

Table 3: Cardiac Health - Spectrum of Diseases - Prevalence in California*

	Prevalence Ranges by Total Population in CA	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	196,840	78,736
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	19,684	7,874
Dilated Cardiomyopathy (DCM)	157,472	15,747
Marfan Syndrome	7,874	591
Early Repolarization Syndrome (ERS)	5,117,850	393,681
Long QT Syndrome (LQTS)	19,684	No data available
Short QT Syndrome (SQTS)	39,368	7,874
Brugada Syndrome (BrS)	19,684	3,937
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	7,874	3,937
Anomalous Aortic Origin of Coronary Artery (AAOCA)	393,681	39,368
Congenital Heart Disease (CHD)	403,523	271,640
Total Population Estimated to be impacted with Cardiac Diseases in California	**6,383,534**	**823,383**

*The cardiac disease prevalence for CA was estimated by multiplying the national prevalence of each disorder and
the population of the state of CA. Prevalence values are based on the known and diagnosed cases. The number of people
who are undiagnosed could be slightly higher.

Table 4: Cardiac Health - Spectrum of Diseases - Prevalence per State Senator's District in California*

	Approximate Prevalence Ranges within Each CA State Senator's Region	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	4,921	1,968
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	492	197
Dilated Cardiomyopathy (DCM)	3,937	394
Marfan Syndrome	197	15
Early Repolarization Syndrome (ERS)	127,946	9,842
Long QT Syndrome (LQTS)	492	No data available
Short QT Syndrome (SQTS)	984	197
Brugada Syndrome (BrS)	492	98
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	197	98
Anomalous Aortic Origin of Coronary Artery (AAOCA)	9,842	984
Congenital Heart Disease (CHD)	10,088	6,791
Total Population Estimated to be impacted with Cardiac Diseases at Each State Senator's Region	**159,588**	**20,585**

*The cardiac disease prevalence for each District in CA was estimated by multiplying the national prevalence of each disorder, and the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Table 5: Cardiac Health - Spectrum of Diseases - Prevalence per Assembly Member's District in California*

	Approximate Prevalence Ranges within Each CA Assembly Member's District	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	2,461	984
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	246	98
Dilated Cardiomyopathy (DCM)	1,968	197
Marfan Syndrome	98	7
Early Repolarization Syndrome (ERS)	63,973	4,921
Long QT Syndrome (LQTS)	246	No data available
Short QT Syndrome (SQTS)	492	98
Brugada Syndrome (BrS)	246	49
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	98	49
Anomalous Aortic Origin of Coronary Artery (AAOCA)	4,921	492
Congenital Heart Disease (CHD)	5,044	3,395
Total Population Estimated to be impacted with Cardiac Diseases at Each Assembly Member's District	**79,794**	**10,292**

*The cardiac disease prevalence for each Assembly Member's District in CA was estimated by multiplying the national prevalence of each disorder, and by the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Illinois State Demographics and Prevalence Data

Table 1: Illinois (IL) State Demographics

Total State Population[1]	12,587,530
Number of Senators[2]	59
Population per Senator[3]	213,348
Number of House Members[4]	118
Population per House Member[5]	106,674
Pediatric Population Percentages (%) (<18 years of age)[6]	22.1
Pediatric Population Calculated (<18 years of age)[7]	2,781,844

Source:

[1]Population Data - SC-EST2020-18+POP-RES: Estimates of the Total Resident Population and Resident Population Age 18 Years and Older for the United States, States, the District of Columbia, and Puerto Rico: July 1, 2020. U.S. Census Bureau, Population Division; Release Date: December 2020, Updated May 2021 with Puerto Rico Estimates

[2] https://ballotpedia.org/Illinois_state_legislative_districts#Senate

[3] Population per Senator is a calculated number. The formula used is (Total State Population/Number of Senators)

[4] https://ballotpedia.org/Illinois_state_legislative_districts#House

[5] Population per House Member is a calculated number. The formula used is (Total State Population/Number of House Members)

[6] SC-EST2020-18+POP-RES

[7] Pediatric Population is calculated number. The formula used is (Pediatric Population Percentages provided in the SC-EST2020-18+POP-RES file multiplied by the State Population).

Table 2: Cardiac Health - Spectrum of Diseases - Prevalence in USA

Disease Type	PREVALENCE RANGES	
	Adult & Pediatric Patients (High End of the Range)	Adult & Pediatric Patients (Low End of the Range)
Hypertrophic Cardiomyopathy (HCM)	0.50%	0.20%
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	0.05%	0.02%
Dilated Cardiomyopathy (DCM)	0.40%	0.04%
Marfan Syndrome	0.02%	0.00%
Early Repolarization Syndrome (ERS)	13.00%	1.00%
Long QT Syndrome (LQTS)	0.05%	No data available
Short QT Syndrome (SQTS)	0.10%	0.02%
Brugada Syndrome (BrS)	0.05%	0.01%
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	0.02%	0.01%
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1.00%	0.10%
Congenital Heart Disease (CHD)	1.03%	0.69%

Source: Cardiac Health - Spectrum of Diseases Prevalence Data & Sources

Table 3: Cardiac Health - Spectrum of Diseases - Prevalence in Illinois*

	Prevalence Ranges by Total Population in IL	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	62,938	25,175
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	6,294	2,518
Dilated Cardiomyopathy (DCM)	50,350	5,035
Marfan Syndrome	2,518	189
Early Repolarization Syndrome (ERS)	1,636,379	125,875
Long QT Syndrome (LQTS)	6,294	No data available
Short QT Syndrome (SQTS)	12,588	2,518
Brugada Syndrome (BrS)	6,294	1,259
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	2,518	1,259
Anomalous Aortic Origin of Coronary Artery (AAOCA)	125,875	12,588
Congenital Heart Disease (CHD)	129,022	86,854
Total Population Estimated to be impacted with Cardiac Diseases in Illinois	**2,041,068**	**263,268**

*The cardiac disease prevalence for IL was estimated by multiplying the national prevalence of each disorder and
the population of the state of IL. Prevalence values are based on the known and diagnosed cases. The number of people
who are undiagnosed could be slightly higher.

Table 4: Cardiac Health - Spectrum of Diseases - Prevalence per State Senator's District in Illinois*

	Approximate Prevalence Ranges within Each IL State Senator's Region	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	1,067	427
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	107	43
Dilated Cardiomyopathy (DCM)	853	85
Marfan Syndrome	43	3
Early Repolarization Syndrome (ERS)	27,735	2,133
Long QT Syndrome (LQTS)	107	No data available
Short QT Syndrome (SQTS)	213	43
Brugada Syndrome (BrS)	107	21
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	43	21
Anomalous Aortic Origin of Coronary Artery (AAOCA)	2,133	213
Congenital Heart Disease (CHD)	2,187	1,472
Total Population Estimated to be impacted with Cardiac Diseases at Each State Senator's District	**34,594**	**4,462**

*The cardiac disease prevalence for each District in IL was estimated by multiplying the national prevalence of each disorder, and the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Table 5: Cardiac Health - Spectrum of Diseases - Prevalence per House Member's District in Illinois*

	Approximate Prevalence Ranges within Each IL House Member's District	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	533	213
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	53	21
Dilated Cardiomyopathy (DCM)	427	43
Marfan Syndrome	21	2
Early Repolarization Syndrome (ERS)	13,868	1,067
Long QT Syndrome (LQTS)	53	No data available
Short QT Syndrome (SQTS)	107	21
Brugada Syndrome (BrS)	53	11
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	21	11
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1,067	107
Congenital Heart Disease (CHD)	1,093	736
Total Population Estimated to be impacted with Cardiac Diseases at Each House Member's District	**17,297**	**2,231**

*The cardiac disease prevalence for each House Member's District in IL was estimated by multiplying the national prevalence of each disorder, and by the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Maryland State Demographics and Prevalence Data

Table 1: Maryland (MD) State Demographics

Total State Population[1]	6,055,802
Number of Senators[2]	47
Population per Senator[3]	128,847
Number of House Delegates[4]	141
Population per House Delegate[5]	42,949
Pediatric Population Percentages (%) (<18 years of age)[6]	22
Pediatric Population Calculated (<18 years of age)[7]	1,332,276

Source:
[1]Population Data - SC-EST2020-18+POP-RES: Estimates of the Total Resident Population and Resident Population Age 18 Years and Older for the United States, States, the District of Columbia, and Puerto Rico: July 1, 2020. U.S. Census Bureau, Population Division; Release Date: December 2020, Updated May 2021 with Puerto Rico Estimates
[2] https://ballotpedia.org/Maryland_state_legislative_districts#Senate
[3] Population per Senator is a calculated number. The formula used is (Total State Population/Number of Senators)
[4] https://ballotpedia.org/Maryland_state_legislative_districts#House
[5] Population per House Delegates is a calculated number. The formula used is (Total State Population/Number of House Delegates)
[6] SC-EST2020-18+POP-RES
[7] Pediatric Population is calculated number. The formula used is (Pediatric Population Percentages provided in the SC-EST2020-18+POP-RES file multiplied by the State Population).

Table 2: Cardiac Health - Spectrum of Diseases - Prevalence in USA

Disease Type	PREVALENCE RANGES	
	Adult & Pediatric Patients (High End of the Range)	Adult & Pediatric Patients (Low End of the Range)
Hypertrophic Cardiomyopathy (HCM)	0.50%	0.20%
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	0.05%	0.02%
Dilated Cardiomyopathy (DCM)	0.40%	0.04%
Marfan Syndrome	0.02%	0.00%
Early Repolarization Syndrome (ERS)	13.00%	1.00%
Long QT Syndrome (LQTS)	0.05%	No data available
Short QT Syndrome (SQTS)	0.10%	0.02%
Brugada Syndrome (BrS)	0.05%	0.01%
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	0.02%	0.01%
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1.00%	0.10%
Congenital Heart Disease (CHD)	1.03%	0.69%

Source: Cardiac Health - Spectrum of Diseases Prevalence Data & Sources

Table 3: Cardiac Health - Spectrum of Diseases - Prevalence in Maryland*

	Prevalence Ranges by Total Population in MD	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	30,279	12,112
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	3,028	1,211
Dilated Cardiomyopathy (DCM)	24,223	2,422
Marfan Syndrome	1,211	91
Early Repolarization Syndrome (ERS)	787,254	60,558
Long QT Syndrome (LQTS)	3,028	No data available
Short QT Syndrome (SQTS)	6,056	1,211
Brugada Syndrome (BrS)	3,028	606
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	1,211	606
Anomalous Aortic Origin of Coronary Artery (AAOCA)	60,558	6,056
Congenital Heart Disease (CHD)	62,072	41,785
Total Population Estimated to be impacted with Cardiac Diseases in Maryland	**981,948**	**126,657**

*The cardiac disease prevalence for MD was estimated by multiplying the national prevalence of each disorder and
the population of the state of MD. Prevalence values are based on the known and diagnosed cases. The number of people
who are undiagnosed could be slightly higher.

Table 4: Cardiac Health - Spectrum of Diseases - Prevalence per State Senator's District in Maryland*

	Approximate Prevalence Ranges within Each MD State Senator's Region	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	644	258
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	64	26
Dilated Cardiomyopathy (DCM)	515	52
Marfan Syndrome	26	2
Early Repolarization Syndrome (ERS)	16,750	1,288
Long QT Syndrome (LQTS)	64	No data available
Short QT Syndrome (SQTS)	129	26
Brugada Syndrome (BrS)	64	13
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	26	13
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1,288	129
Congenital Heart Disease (CHD)	1,321	889
Total Population Estimated to be impacted with Cardiac Diseases at Each State Senator's District	**20,893**	**2,695**

*The cardiac disease prevalence for each District in MD was estimated by multiplying the national prevalence of each disorder, and the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Table 5: Cardiac Health - Spectrum of Diseases - Prevalence per House Delegate's District in Maryland*

	Approximate Prevalence Ranges within Each MD House Delegate's District	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	215	86
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	21	9
Dilated Cardiomyopathy (DCM)	172	17
Marfan Syndrome	9	1
Early Repolarization Syndrome (ERS)	5,583	429
Long QT Syndrome (LQTS)	21	No data available
Short QT Syndrome (SQTS)	43	9
Brugada Syndrome (BrS)	21	4
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	9	4
Anomalous Aortic Origin of Coronary Artery (AAOCA)	429	43
Congenital Heart Disease (CHD)	440	296
Total Population Estimated to be impacted with Cardiac Diseases at Each House Delegate's District	**6,964**	**898**

*The cardiac disease prevalence for each House Delegate's District in MD was estimated by multiplying the national prevalence of each disorder, and by the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Massachusetts State Demographics and Prevalence Data

Table 1: Massachusetts (MA) State Demographics

Total State Population[1]	6,893,574
Number of Senators[2]	40
Population per Senator[3]	172,339
Number of House Representatives[4]	160
Population per House Representative[5]	43,085
Pediatric Population Percentages (%) (<18 years of age)[6]	19.5
Pediatric Population Calculated (<18 years of age)[7]	1,344,247

Source:

[1]Population Data - SC-EST2020-18+POP-RES: Estimates of the Total Resident Population and Resident Population Age 18 Years and Older for the United States, States, the District of Columbia, and Puerto Rico: July 1, 2020. U.S. Census Bureau, Population Division; Release Date: December 2020, Updated May 2021 with Puerto Rico Estimates

[2] https://ballotpedia.org/Massachusetts_state_legislative_districts#Senate

[3] Population per Senator is a calculated number. The formula used is (Total State Population/Number of Senators)

[4] https://ballotpedia.org/Massachusetts_state_legislative_districts#House

[5] Population per House Representatives is a calculated number. The formula used is (Total State Population/Number of House Representatives)

[6] SC-EST2020-18+POP-RES

[7] Pediatric Population is calculated number. The formula used is (Pediatric Population Percentages provided in the SC-EST2020-18+POP-RES file multiplied by the State Population).

Table 2: Cardiac Health - Spectrum of Diseases - Prevalence in USA

Disease Type	PREVALENCE RANGES	
	Adult & Pediatric Patients (High End of the Range)	Adult & Pediatric Patients (Low End of the Range)
Hypertrophic Cardiomyopathy (HCM)	0.50%	0.20%
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	0.05%	0.02%
Dilated Cardiomyopathy (DCM)	0.40%	0.04%
Marfan Syndrome	0.02%	0.00%
Early Repolarization Syndrome (ERS)	13.00%	1.00%
Long QT Syndrome (LQTS)	0.05%	No data available
Short QT Syndrome (SQTS)	0.10%	0.02%
Brugada Syndrome (BrS)	0.05%	0.01%
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	0.02%	0.01%
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1.00%	0.10%
Congenital Heart Disease (CHD)	1.03%	0.69%

Source: Cardiac Health - Spectrum of Diseases Prevalence Data & Sources

Table 3: Cardiac Health - Spectrum of Diseases - Prevalence in Massachusetts*

	Prevalence Ranges by Total Population in MA	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	34,468	13,787
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	3,447	1,379
Dilated Cardiomyopathy (DCM)	27,574	2,757
Marfan Syndrome	1,379	103
Early Repolarization Syndrome (ERS)	896,165	68,936
Long QT Syndrome (LQTS)	3,447	No data available
Short QT Syndrome (SQTS)	6,894	1,379
Brugada Syndrome (BrS)	3,447	689
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	1,379	689
Anomalous Aortic Origin of Coronary Artery (AAOCA)	68,936	6,894
Congenital Heart Disease (CHD)	70,659	47,566
Total Population Estimated to be impacted with Cardiac Diseases in Massachusetts	**1,117,793**	**144,179**

*The cardiac disease prevalence for MA was estimated by multiplying the national prevalence of each disorder and
the population of the state of MA. Prevalence values are based on the known and diagnosed cases. The number of people
who are undiagnosed could be slightly higher.

Table 4: Cardiac Health - Spectrum of Diseases - Prevalence per State Senator's District in Massachusetts*

	Approximate Prevalence Ranges within Each MA State Senator's Region	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	862	345
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	86	34
Dilated Cardiomyopathy (DCM)	689	69
Marfan Syndrome	34	3
Early Repolarization Syndrome (ERS)	22,404	1,723
Long QT Syndrome (LQTS)	86	No data available
Short QT Syndrome (SQTS)	172	34
Brugada Syndrome (BrS)	86	17
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	34	17
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1,723	172
Congenital Heart Disease (CHD)	1,766	1,189
Total Population Estimated to be impacted with Cardiac Diseases at Each State Senator's District	**27,945**	**3,604**

*The cardiac disease prevalence for each District in MA was estimated by multiplying the national prevalence of each disorder, and the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Table 5: Cardiac Health - Spectrum of Diseases - Prevalence per House Representative's District in Massachusetts*

	Approximate Prevalence Ranges within Each MA House Representative's District	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	215	86
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	22	9
Dilated Cardiomyopathy (DCM)	172	17
Marfan Syndrome	9	1
Early Repolarization Syndrome (ERS)	5,601	431
Long QT Syndrome (LQTS)	22	No data available
Short QT Syndrome (SQTS)	43	9
Brugada Syndrome (BrS)	22	4
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	9	4
Anomalous Aortic Origin of Coronary Artery (AAOCA)	431	43
Congenital Heart Disease (CHD)	442	297
Total Population Estimated to be impacted with Cardiac Diseases at Each House Representative's District	**6,986**	**901**

*The cardiac disease prevalence for each House Representative's District in MA was estimated by multiplying the national prevalence of each disorder, and by the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Michigan State Demographics and Prevalence Data

Table 1: Michigan (MI) State Demographics

Total State Population[1]	9,966,555
Number of Senators[2]	38
Population per Senator[3]	262,278
Number of House Representatives[4]	110
Population per House Representative[5]	90,605
Pediatric Population Percentages (%) (<18 years of age)[6]	21.3
Pediatric Population Calculated (<18 years of age)[7]	2,122,876

Source:

[1]Population Data - SC-EST2020-18+POP-RES: Estimates of the Total Resident Population and Resident Population Age 18 Years and Older for the United States, States, the District of Columbia, and Puerto Rico: July 1, 2020. U.S. Census Bureau, Population Division; Release Date: December 2020, Updated May 2021 with Puerto Rico Estimates

[2] https://ballotpedia.org/Michigan_state_legislative_districts#Senate

[3] Population per Senator is a calculated number. The formula used is (Total State Population/Number of Senators)

[4] https://ballotpedia.org/Michigan_state_legislative_districts#House

[5] Population per House Representatives is a calculated number. The formula used is (Total State Population/Number of House Representatives)

[6] SC-EST2020-18+POP-RES

[7] Pediatric Population is calculated number. The formula used is (Pediatric Population Percentages provided in the SC-EST2020-18+POP-RES file multiplied by the State Population).

Table 2: Cardiac Health - Spectrum of Diseases - Prevalence in USA

Disease Type	PREVALENCE RANGES	
	Adult & Pediatric Patients (High End of the Range)	Adult & Pediatric Patients (Low End of the Range)
Hypertrophic Cardiomyopathy (HCM)	0.50%	0.20%
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	0.05%	0.02%
Dilated Cardiomyopathy (DCM)	0.40%	0.04%
Marfan Syndrome	0.02%	0.00%
Early Repolarization Syndrome (ERS)	13.00%	1.00%
Long QT Syndrome (LQTS)	0.05%	No data available
Short QT Syndrome (SQTS)	0.10%	0.02%
Brugada Syndrome (BrS)	0.05%	0.01%
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	0.02%	0.01%
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1.00%	0.10%
Congenital Heart Disease (CHD)	1.03%	0.69%

Source: Cardiac Health - Spectrum of Diseases Prevalence Data & Sources

Table 3: Cardiac Health - Spectrum of Diseases - Prevalence in Michigan*

	Prevalence Ranges by Total Population in MI	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	49,833	19,933
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	4,983	1,993
Dilated Cardiomyopathy (DCM)	39,866	3,987
Marfan Syndrome	1,993	149
Early Repolarization Syndrome (ERS)	1,295,652	99,666
Long QT Syndrome (LQTS)	4,983	No data available
Short QT Syndrome (SQTS)	9,967	1,993
Brugada Syndrome (BrS)	4,983	997
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	1,993	997
Anomalous Aortic Origin of Coronary Artery (AAOCA)	99,666	9,967
Congenital Heart Disease (CHD)	102,157	68,769
Total Population Estimated to be impacted with Cardiac Diseases in Michigan	**1,616,077**	**208,450**

*The cardiac disease prevalence for MI was estimated by multiplying the national prevalence of each disorder and
the population of the state of MI. Prevalence values are based on the known and diagnosed cases. The number of people
who are undiagnosed could be slightly higher.

Table 4: Cardiac Health - Spectrum of Diseases - Prevalence per State Senator's District in Michigan*

	Approximate Prevalence Ranges within Each MI State Senator's Region	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	1,311	525
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	131	52
Dilated Cardiomyopathy (DCM)	1,049	105
Marfan Syndrome	52	4
Early Repolarization Syndrome (ERS)	34,096	2,623
Long QT Syndrome (LQTS)	131	No data available
Short QT Syndrome (SQTS)	262	52
Brugada Syndrome (BrS)	131	26
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	52	26
Anomalous Aortic Origin of Coronary Artery (AAOCA)	2,623	262
Congenital Heart Disease (CHD)	2,688	1,810
Total Population Estimated to be impacted with Cardiac Diseases at Each State Senator's District	**42,528**	**5,486**

*The cardiac disease prevalence for each District in MI was estimated by multiplying the national prevalence of each disorder, and the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Table 5: Cardiac Health - Spectrum of Diseases - Prevalence per House Representative's District in Michigan*

	Approximate Prevalence Ranges within Each MI House Representative's District	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	453	181
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	45	18
Dilated Cardiomyopathy (DCM)	362	36
Marfan Syndrome	18	1
Early Repolarization Syndrome (ERS)	11,779	906
Long QT Syndrome (LQTS)	45	No data available
Short QT Syndrome (SQTS)	91	18
Brugada Syndrome (BrS)	45	9
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	18	9
Anomalous Aortic Origin of Coronary Artery (AAOCA)	906	91
Congenital Heart Disease (CHD)	929	625
Total Population Estimated to be impacted with Cardiac Diseases at Each House Representative's District	**14,692**	**1,895**

*The cardiac disease prevalence for each House Representative's District in MI was estimated by multiplying the national prevalence of each disorder, and by the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

New Jersey State Demographics and Prevalence Data

Table 1: New Jersey (NJ) State Demographics

Total State Population[1]	8,882,371
Number of Senators[2]	40
Population per Senator[3]	222,059
Number of General Assemblymen[4]	80
Population per Assembly Member[5]	111,030
Pediatric Population Percentages (%) (<18 years of age)[6]	21.8
Pediatric Population Calculated (<18 years of age)[7]	1,936,357

Source:

[1]Population Data - SC-EST2020-18+POP-RES: Estimates of the Total Resident Population and Resident Population Age 18 Years and Older for the United States, States, the District of Columbia, and Puerto Rico: July 1, 2020. U.S. Census Bureau, Population Division; Release Date: December 2020, Updated May 2021 with Puerto Rico Estimates

[2] https://ballotpedia.org/New_Jersey_state_legislative_districts#Senate

[3] Population per Senator is a calculated number. The formula used is (Total State Population/Number of Senators)

[4] https://ballotpedia.org/New_Jersey_state_legislative_districts#House

[5] Population per General Assemblymen is a calculated number. The formula used is (Total State Population/Number of Assembly Member)

[6] SC-EST2020-18+POP-RES

[7] Pediatric Population is calculated number. The formula used is (Pediatric Population Percentages provided in the SC-EST2020-18+POP-RES file multiplied by the State Population).

Table 2: Cardiac Health - Spectrum of Diseases - Prevalence in USA

Disease Type	PREVALENCE RANGES	
	Adult & Pediatric Patients (High End of the Range)	Adult & Pediatric Patients (Low End of the Range)
Hypertrophic Cardiomyopathy (HCM)	0.50%	0.20%
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	0.05%	0.02%
Dilated Cardiomyopathy (DCM)	0.40%	0.04%
Marfan Syndrome	0.02%	0.00%
Early Repolarization Syndrome (ERS)	13.00%	1.00%
Long QT Syndrome (LQTS)	0.05%	No data available
Short QT Syndrome (SQTS)	0.10%	0.02%
Brugada Syndrome (BrS)	0.05%	0.01%
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	0.02%	0.01%
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1.00%	0.10%
Congenital Heart Disease (CHD)	1.03%	0.69%

Source: Cardiac Health - Spectrum of Diseases Prevalence Data & Sources

Table 3: Cardiac Health - Spectrum of Diseases - Prevalence in New Jersey*

	Prevalence Ranges by Total Population in NJ	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	44,412	17,765
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	4,441	1,776
Dilated Cardiomyopathy (DCM)	35,529	3,553
Marfan Syndrome	1,776	133
Early Repolarization Syndrome (ERS)	1,154,708	88,824
Long QT Syndrome (LQTS)	4,441	No data available
Short QT Syndrome (SQTS)	8,882	1,776
Brugada Syndrome (BrS)	4,441	888
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	1,776	888
Anomalous Aortic Origin of Coronary Artery (AAOCA)	88,824	8,882
Congenital Heart Disease (CHD)	91,044	61,288
Total Population Estimated to be impacted with Cardiac Diseases in New Jersey	**1,440,276**	**185,775**

*The cardiac disease prevalence for NJ was estimated by multiplying the national prevalence of each disorder and
the population of the state of NJ. Prevalence values are based on the known and diagnosed cases. The number of people
who are undiagnosed could be slightly higher.

Table 4: Cardiac Health - Spectrum of Diseases - Prevalence per State Senator's District in New Jersey*

	Approximate Prevalence Ranges within Each NJ State Senator's Region	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	1,110	444
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	111	44
Dilated Cardiomyopathy (DCM)	888	89
Marfan Syndrome	44	3
Early Repolarization Syndrome (ERS)	28,868	2,221
Long QT Syndrome (LQTS)	111	No data available
Short QT Syndrome (SQTS)	222	44
Brugada Syndrome (BrS)	111	22
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	44	22
Anomalous Aortic Origin of Coronary Artery (AAOCA)	2,221	222
Congenital Heart Disease (CHD)	2,276	1,532
Total Population Estimated to be impacted with Cardiac Diseases at Each State Senator's District	**36,007**	**4,644**

*The cardiac disease prevalence for each District in NJ was estimated by multiplying the national prevalence of each disorder, and the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Table 5: Cardiac Health - Spectrum of Diseases - Prevalence per General Assemblymen's District in New Jersey*

	Approximate Prevalence Ranges within Each NJ General Assemblymen's District	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	555	222
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	56	22
Dilated Cardiomyopathy (DCM)	444	44
Marfan Syndrome	22	2
Early Repolarization Syndrome (ERS)	14,434	1,110
Long QT Syndrome (LQTS)	56	No data available
Short QT Syndrome (SQTS)	111	22
Brugada Syndrome (BrS)	56	11
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	22	11
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1,110	111
Congenital Heart Disease (CHD)	1,138	766
Total Population Estimated to be impacted with Cardiac Diseases at Each General Assemblymen's District	**18,003**	**2,322**

*The cardiac disease prevalence for each General Assemblymen's District in NJ was estimated by multiplying the national prevalence of each disorder, and by the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

New York State Demographics and Prevalence Data

Table 1: New York (NY) State Demographics

Total State Population[1]	19,336,776
Number of Senators[2]	63
Population per Senator[3]	306,933
Number of Assembly Members[4]	150
Population per Assembly Member[5]	128,912
Pediatric Population Percentages (%) (<18 years of age)[6]	20.6
Pediatric Population Calculated (<18 years of age)[7]	3,983,376

Source:

[1]Population Data - SC-EST2020-18+POP-RES: Estimates of the Total Resident Population and Resident Population Age 18 Years and Older for the United States, States, the District of Columbia, and Puerto Rico: July 1, 2020. U.S. Census Bureau, Population Division; Release Date: December 2020, Updated May 2021 with Puerto Rico Estimates

[2] https://ballotpedia.org/New_York_state_legislative_districts#Senate

[3] Population per Senator is a calculated number. The formula used is (Total State Population/Number of Senators)

[4] https://ballotpedia.org/New_York_state_legislative_districts#House

[5] Population per Assembly Member is a calculated number. The formula used is (Total State Population/Number of Assembly Member)

[6] SC-EST2020-18+POP-RES

[7] Pediatric Population is calculated number. The formula used is (Pediatric Population Percentages provided in the SC-EST2020-18+POP-RES file multiplied by the State Population).

Table 2: Cardiac Health - Spectrum of Diseases - Prevalence in USA

Disease Type	PREVALENCE RANGES	
	Adult & Pediatric Patients (High End of the Range)	Adult & Pediatric Patients (Low End of the Range)
Hypertrophic Cardiomyopathy (HCM)	0.50%	0.20%
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	0.05%	0.02%
Dilated Cardiomyopathy (DCM)	0.40%	0.04%
Marfan Syndrome	0.02%	0.00%
Early Repolarization Syndrome (ERS)	13.00%	1.00%
Long QT Syndrome (LQTS)	0.05%	No data available
Short QT Syndrome (SQTS)	0.10%	0.02%
Brugada Syndrome (BrS)	0.05%	0.01%
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	0.02%	0.01%
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1.00%	0.10%
Congenital Heart Disease (CHD)	1.03%	0.69%

Source: Cardiac Health - Spectrum of Diseases Prevalence Data & Sources

Table 3: Cardiac Health - Spectrum of Diseases - Prevalence in New York*

	Prevalence Ranges by Total Population in NY	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	96,684	38,674
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	9,668	3,867
Dilated Cardiomyopathy (DCM)	77,347	7,735
Marfan Syndrome	3,867	290
Early Repolarization Syndrome (ERS)	2,513,781	193,368
Long QT Syndrome (LQTS)	9,668	No data available
Short QT Syndrome (SQTS)	19,337	3,867
Brugada Syndrome (BrS)	9,668	1,934
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	3,867	1,934
Anomalous Aortic Origin of Coronary Artery (AAOCA)	193,368	19,337
Congenital Heart Disease (CHD)	198,202	133,424
Total Population Estimated to be impacted with Cardiac Diseases in New York	**3,135,458**	**404,429**

*The cardiac disease prevalence for NY was estimated by multiplying the national prevalence of each disorder and
the population of the state of NY. Prevalence values are based on the known and diagnosed cases. The number of people
who are undiagnosed could be slightly higher.

Table 4: Cardiac Health - Spectrum of Diseases - Prevalence per State Senator's District in New York*

	Approximate Prevalence Ranges within Each NY State Senator's Region	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	1,535	614
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	153	61
Dilated Cardiomyopathy (DCM)	1,228	123
Marfan Syndrome	61	5
Early Repolarization Syndrome (ERS)	39,901	3,069
Long QT Syndrome (LQTS)	153	No data available
Short QT Syndrome (SQTS)	307	61
Brugada Syndrome (BrS)	153	31
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	61	31
Anomalous Aortic Origin of Coronary Artery (AAOCA)	3,069	307
Congenital Heart Disease (CHD)	3,146	2,118
Total Population Estimated to be impacted with Cardiac Diseases at Each State Senator's District	**49,769**	**6,420**

*The cardiac disease prevalence for each District in NY was estimated by multiplying the national prevalence of each disorder, and the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Table 5: Cardiac Health - Spectrum of Diseases - Prevalence per Assembly Member's District in New York*

	Approximate Prevalence Ranges within Each NY Assembly Member's District	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	645	258
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	64	26
Dilated Cardiomyopathy (DCM)	516	52
Marfan Syndrome	26	2
Early Repolarization Syndrome (ERS)	16,759	1,289
Long QT Syndrome (LQTS)	64	No data available
Short QT Syndrome (SQTS)	129	26
Brugada Syndrome (BrS)	64	13
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	26	13
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1,289	129
Congenital Heart Disease (CHD)	1,321	889
Total Population Estimated to be impacted with Cardiac Diseases at Each Assembly Member's District	**20,903**	**2,696**

*The cardiac disease prevalence for each Assembly Member's District in NY was estimated by multiplying the national prevalence of each disorder, and by the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Ohio State Demographics and Prevalence Data

Table 1: Ohio (OH) State Demographics

Total State Population[1]	11,693,217
Number of Senators[2]	33
Population per Senator[3]	354,340
Number of House Representatives[4]	99
Population per House Representative[5]	118,113
Pediatric Population Percentages (%) (<18 years of age)[6]	22
Pediatric Population Calculated (<18 years of age)[7]	2,572,508

Source:

[1]Population Data - SC-EST2020-18+POP-RES: Estimates of the Total Resident Population and Resident Population Age 18 Years and Older for the United States, States, the District of Columbia, and Puerto Rico: July 1, 2020. U.S. Census Bureau, Population Division; Release Date: December 2020, Updated May 2021 with Puerto Rico Estimates

[2] https://ballotpedia.org/Ohio_state_legislative_districts#Senate

[3] Population per Senator is a calculated number. The formula used is (Total State Population/Number of Senators)

[4] https://ballotpedia.org/Ohio_state_legislative_districts#House

[5] Population per House Representative is a calculated number. The formula used is (Total State Population/Number of House Representatives)

[6] SC-EST2020-18+POP-RES

[7] Pediatric Population is calculated number. The formula used is (Pediatric Population Percentages provided in the SC-EST2020-18+POP-RES file multiplied by the State Population).

Table 2: Cardiac Health - Spectrum of Diseases - Prevalence in USA

Disease Type	PREVALENCE RANGES	
	Adult & Pediatric Patients (High End of the Range)	Adult & Pediatric Patients (Low End of the Range)
Hypertrophic Cardiomyopathy (HCM)	0.50%	0.20%
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	0.05%	0.02%
Dilated Cardiomyopathy (DCM)	0.40%	0.04%
Marfan Syndrome	0.02%	0.00%
Early Repolarization Syndrome (ERS)	13.00%	1.00%
Long QT Syndrome (LQTS)	0.05%	No data available
Short QT Syndrome (SQTS)	0.10%	0.02%
Brugada Syndrome (BrS)	0.05%	0.01%
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	0.02%	0.01%
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1.00%	0.10%
Congenital Heart Disease (CHD)	1.03%	0.69%

Source: Cardiac Health - Spectrum of Diseases Prevalence Data & Sources

Table 3: Cardiac Health - Spectrum of Diseases - Prevalence in Ohio*

	Prevalence Ranges by Total Population in OH	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	58,466	23,386
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	5,847	2,339
Dilated Cardiomyopathy (DCM)	46,773	4,677
Marfan Syndrome	2,339	175
Early Repolarization Syndrome (ERS)	1,520,118	116,932
Long QT Syndrome (LQTS)	5,847	No data available
Short QT Syndrome (SQTS)	11,693	2,339
Brugada Syndrome (BrS)	5,847	1,169
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	2,339	1,169
Anomalous Aortic Origin of Coronary Artery (AAOCA)	116,932	11,693
Congenital Heart Disease (CHD)	119,855	80,683
Total Population Estimated to be impacted with Cardiac Diseases in Ohio	**1,896,055**	**244,564**

*The cardiac disease prevalence for OH was estimated by multiplying the national prevalence of each disorder and
the population of the state of OH. Prevalence values are based on the known and diagnosed cases. The number of people
who are undiagnosed could be slightly higher.

Table 4: Cardiac Health - Spectrum of Diseases - Prevalence per State Senator's District in Ohio*

	Approximate Prevalence Ranges within Each OH State Senator's Region	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	1,772	709
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	177	71
Dilated Cardiomyopathy (DCM)	1,417	142
Marfan Syndrome	71	5
Early Repolarization Syndrome (ERS)	46,064	3,543
Long QT Syndrome (LQTS)	177	No data available
Short QT Syndrome (SQTS)	354	71
Brugada Syndrome (BrS)	177	35
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	71	35
Anomalous Aortic Origin of Coronary Artery (AAOCA)	3,543	354
Congenital Heart Disease (CHD)	3,632	2,445
Total Population Estimated to be impacted with Cardiac Diseases at Each State Senator's District	**57,456**	**7,411**

*The cardiac disease prevalence for each District in OH was estimated by multiplying the national prevalence of each disorder, and the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Table 5: Cardiac Health - Spectrum of Diseases - Prevalence per House Representative's District in Ohio*

	Approximate Prevalence Ranges within Each OH House Representative's District	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	591	236
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	59	24
Dilated Cardiomyopathy (DCM)	472	47
Marfan Syndrome	24	2
Early Repolarization Syndrome (ERS)	15,355	1,181
Long QT Syndrome (LQTS)	59	No data available
Short QT Syndrome (SQTS)	118	24
Brugada Syndrome (BrS)	59	12
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	24	12
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1,181	118
Congenital Heart Disease (CHD)	1,211	815
Total Population Estimated to be impacted with Cardiac Diseases at Each House Representative's District	**19,152**	**2,470**

*The cardiac disease prevalence for each House Representative's District in OH was estimated by multiplying the national prevalence of each disorder, and by the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Pennsylvania State Demographics and Prevalence Data

Table 1: Pennsylvania (PA) State Demographics

Total State Population[1]	12,783,254
Number of Senators[2]	50
Population per Senator[3]	255,665
Number of House Representatives[4]	203
Population per House Representative[5]	62,972
Pediatric Population Percentages (%) (<18 years of age)[6]	20.5
Pediatric Population Calculated (<18 years of age)[7]	2,620,567

Source:

[1]Population Data - SC-EST2020-18+POP-RES: Estimates of the Total Resident Population and Resident Population Age 18 Years and Older for the United States, States, the District of Columbia, and Puerto Rico: July 1, 2020. U.S. Census Bureau, Population Division; Release Date: December 2020, Updated May 2021 with Puerto Rico Estimates

[2] https://ballotpedia.org/Pennsylvania_state_legislative_districts#Senate

[3] Population per Senator is a calculated number. The formula used is (Total State Population/Number of Senators)

[4] https://ballotpedia.org/Pennsylvania_state_legislative_districts#House

[5] Population per House Representative is a calculated number. The formula used is (Total State Population/Number of House Representatives)

[6] SC-EST2020-18+POP-RES

[7] Pediatric Population is calculated number. The formula used is (Pediatric Population Percentages provided in the SC-EST2020-18+POP-RES file multiplied by the State Population).

Table 2: Cardiac Health - Spectrum of Diseases - Prevalence in USA

Disease Type	PREVALENCE RANGES	
	Adult & Pediatric Patients (High End of the Range)	Adult & Pediatric Patients (Low End of the Range)
Hypertrophic Cardiomyopathy (HCM)	0.50%	0.20%
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	0.05%	0.02%
Dilated Cardiomyopathy (DCM)	0.40%	0.04%
Marfan Syndrome	0.02%	0.00%
Early Repolarization Syndrome (ERS)	13.00%	1.00%
Long QT Syndrome (LQTS)	0.05%	No data available
Short QT Syndrome (SQTS)	0.10%	0.02%
Brugada Syndrome (BrS)	0.05%	0.01%
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	0.02%	0.01%
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1.00%	0.10%
Congenital Heart Disease (CHD)	1.03%	0.69%

Source: Cardiac Health - Spectrum of Diseases Prevalence Data & Sources

Table 3: Cardiac Health - Spectrum of Diseases - Prevalence in Pennsylvania*

	Prevalence Ranges by Total Population in PA	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	63,916	25,567
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	6,392	2,557
Dilated Cardiomyopathy (DCM)	51,133	5,113
Marfan Syndrome	2,557	192
Early Repolarization Syndrome (ERS)	1,661,823	127,833
Long QT Syndrome (LQTS)	6,392	No data available
Short QT Syndrome (SQTS)	12,783	2,557
Brugada Syndrome (BrS)	6,392	1,278
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	2,557	1,278
Anomalous Aortic Origin of Coronary Artery (AAOCA)	127,833	12,783
Congenital Heart Disease (CHD)	131,028	88,204
Total Population Estimated to be impacted with Cardiac Diseases in Pennsylvania	**2,072,805**	**267,362**

*The cardiac disease prevalence for PA was estimated by multiplying the national prevalence of each disorder and
the population of the state of PA. Prevalence values are based on the known and diagnosed cases. The number of people
who are undiagnosed could be slightly higher.

Table 4: Cardiac Health - Spectrum of Diseases - Prevalence per State Senator's District in Pennsylvania*

	Approximate Prevalence Ranges within Each PA State Senator's Region	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	1,278	511
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	128	51
Dilated Cardiomyopathy (DCM)	1,023	102
Marfan Syndrome	51	4
Early Repolarization Syndrome (ERS)	33,236	2,557
Long QT Syndrome (LQTS)	128	No data available
Short QT Syndrome (SQTS)	256	51
Brugada Syndrome (BrS)	128	26
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	51	26
Anomalous Aortic Origin of Coronary Artery (AAOCA)	2,557	256
Congenital Heart Disease (CHD)	2,621	1,764
Total Population Estimated to be impacted with Cardiac Diseases at Each State Senator's District	**41,456**	**5,347**

*The cardiac disease prevalence for each District in PA was estimated by multiplying the national prevalence of each disorder, and the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Table 5: Cardiac Health - Spectrum of Diseases - Prevalence per House Representative's District in Pennsylvania*

	Approximate Prevalence Ranges within Each PA House Representative's District	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	315	126
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	31	13
Dilated Cardiomyopathy (DCM)	252	25
Marfan Syndrome	13	1
Early Repolarization Syndrome (ERS)	8,186	630
Long QT Syndrome (LQTS)	31	No data available
Short QT Syndrome (SQTS)	63	13
Brugada Syndrome (BrS)	31	6
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	13	6
Anomalous Aortic Origin of Coronary Artery (AAOCA)	630	63
Congenital Heart Disease (CHD)	645	435
Total Population Estimated to be impacted with Cardiac Diseases at Each House Representative's District	**10,211**	**1,317**

*The cardiac disease prevalence for each House Representative's District in PA was estimated by multiplying the national prevalence of each disorder, and by the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Texas State Demographics and Prevalence Data

Table 1: Texas (TX) State Demographics

Total State Population[1]	29,360,759
Number of Senators[2]	31
Population per Senator[3]	947,121
Number of House Representatives[4]	150
Population per House Representative[5]	195,738
Pediatric Population Percentages (%) (<18 years of age)[6]	25.3
Pediatric Population Calculated (<18 years of age)[7]	7,428,272

Source:

[1]Population Data - SC-EST2020-18+POP-RES: Estimates of the Total Resident Population and Resident Population Age 18 Years and Older for the United States, States, the District of Columbia, and Puerto Rico: July 1, 2020. U.S. Census Bureau, Population Division; Release Date: December 2020, Updated May 2021 with Puerto Rico Estimates

[2] https://ballotpedia.org/Texas_state_legislative_districts#Senate

[3] Population per Senator is a calculated number. The formula used is (Total State Population/Number of Senators)

[4] https://ballotpedia.org/Texas_state_legislative_districts#House

[5] Population per House Representative is a calculated number. The formula used is (Total State Population/Number of House Representatives)

[6] SC-EST2020-18+POP-RES

[7] Pediatric Population is calculated number. The formula used is (Pediatric Population Percentages provided in the SC-EST2020-18+POP-RES file multiplied by the State Population).

Table 2: Cardiac Health - Spectrum of Diseases - Prevalence in USA

Disease Type	PREVALENCE RANGES	
	Adult & Pediatric Patients (High End of the Range)	Adult & Pediatric Patients (Low End of the Range)
Hypertrophic Cardiomyopathy (HCM)	0.50%	0.20%
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	0.05%	0.02%
Dilated Cardiomyopathy (DCM)	0.40%	0.04%
Marfan Syndrome	0.02%	0.00%
Early Repolarization Syndrome (ERS)	13.00%	1.00%
Long QT Syndrome (LQTS)	0.05%	No data available
Short QT Syndrome (SQTS)	0.10%	0.02%
Brugada Syndrome (BrS)	0.05%	0.01%
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	0.02%	0.01%
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1.00%	0.10%
Congenital Heart Disease (CHD)	1.03%	0.69%

Source: Cardiac Health - Spectrum of Diseases Prevalence Data & Sources

Table 3: Cardiac Health - Spectrum of Diseases - Prevalence in Texas*

	Prevalence Ranges by Total Population in TX	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	146,804	58,722
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	14,680	5,872
Dilated Cardiomyopathy (DCM)	117,443	11,744
Marfan Syndrome	5,872	440
Early Repolarization Syndrome (ERS)	3,816,899	293,608
Long QT Syndrome (LQTS)	14,680	No data available
Short QT Syndrome (SQTS)	29,361	5,872
Brugada Syndrome (BrS)	14,680	2,936
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	5,872	2,936
Anomalous Aortic Origin of Coronary Artery (AAOCA)	293,608	29,361
Congenital Heart Disease (CHD)	300,948	202,589
Total Population Estimated to be impacted with Cardiac Diseases in Texas	**4,760,847**	**614,080**

*The cardiac disease prevalence for TX was estimated by multiplying the national prevalence of each disorder and
the population of the state of TX. Prevalence values are based on the known and diagnosed cases. The number of people
who are undiagnosed could be slightly higher.

Table 4: Cardiac Health - Spectrum of Diseases - Prevalence per State Senator's District in Texas*

	Approximate Prevalence Ranges within Each TX State Senator's Region	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	4,736	1,894
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	474	189
Dilated Cardiomyopathy (DCM)	3,788	379
Marfan Syndrome	189	14
Early Repolarization Syndrome (ERS)	123,126	9,471
Long QT Syndrome (LQTS)	474	No data available
Short QT Syndrome (SQTS)	947	189
Brugada Syndrome (BrS)	474	95
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	189	95
Anomalous Aortic Origin of Coronary Artery (AAOCA)	9,471	947
Congenital Heart Disease (CHD)	9,708	6,535
Total Population Estimated to be impacted with Cardiac Diseases at Each State Senator's District	**153,576**	**19,809**

*The cardiac disease prevalence for each District in TX was estimated by multiplying the national prevalence of each disorder, and the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Table 5: Cardiac Health - Spectrum of Diseases - Prevalence per House Representative's District in Texas*

	Approximate Prevalence Ranges within Each TX House Representative's District	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	979	391
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	98	39
Dilated Cardiomyopathy (DCM)	783	78
Marfan Syndrome	39	3
Early Repolarization Syndrome (ERS)	25,446	1,957
Long QT Syndrome (LQTS)	98	No data available
Short QT Syndrome (SQTS)	196	39
Brugada Syndrome (BrS)	98	20
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	39	20
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1,957	196
Congenital Heart Disease (CHD)	2,006	1,351
Total Population Estimated to be impacted with Cardiac Diseases at Each House Representative's District	**31,739**	**4,094**

*The cardiac disease prevalence for each House Representative's District in TX was estimated by multiplying the national prevalence of each disorder, and by the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Utah State Demographics and Prevalence Data

Table 1: Utah (UT) State Demographics

Total State Population[1]	3,249,879
Number of Senators[2]	29
Population per Senator[3]	112,065
Number of House Representatives[4]	75
Population per House Representative[5]	43,332
Pediatric Population Percentages (%) (<18 years of age)[6]	28.6
Pediatric Population Calculated (<18 years of age)[7]	929,465

Source:
[1]Population Data - SC-EST2020-18+POP-RES: Estimates of the Total Resident Population and Resident Population Age 18 Years and Older for the United States, States, the District of Columbia, and Puerto Rico: July 1, 2020. U.S. Census Bureau, Population Division; Release Date: December 2020, Updated May 2021 with Puerto Rico Estimates
[2] https://ballotpedia.org/Utah_state_legislative_districts#Senate
[3] Population per Senator is a calculated number. The formula used is (Total State Population/Number of Senators)
[4] https://ballotpedia.org/Utah_state_legislative_districts#House
[5] Population per House Representative is a calculated number. The formula used is (Total State Population/Number of House Representatives)
[6] SC-EST2020-18+POP-RES
[7] Pediatric Population is calculated number. The formula used is (Pediatric Population Percentages provided in the SC-EST2020-18+POP-RES file multiplied by the State Population).

Table 2: Cardiac Health - Spectrum of Diseases - Prevalence in USA

Disease Type	PREVALENCE RANGES	
	Adult & Pediatric Patients (High End of the Range)	Adult & Pediatric Patients (Low End of the Range)
Hypertrophic Cardiomyopathy (HCM)	0.50%	0.20%
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	0.05%	0.02%
Dilated Cardiomyopathy (DCM)	0.40%	0.04%
Marfan Syndrome	0.02%	0.00%
Early Repolarization Syndrome (ERS)	13.00%	1.00%
Long QT Syndrome (LQTS)	0.05%	No data available
Short QT Syndrome (SQTS)	0.10%	0.02%
Brugada Syndrome (BrS)	0.05%	0.01%
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	0.02%	0.01%
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1.00%	0.10%
Congenital Heart Disease (CHD)	1.03%	0.69%

Source: Cardiac Health - Spectrum of Diseases Prevalence Data & Sources

Table 3: Cardiac Health - Spectrum of Diseases - Prevalence in Utah*

	Prevalence Ranges by Total Population in UT	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	16,249	6,500
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	1,625	650
Dilated Cardiomyopathy (DCM)	13,000	1,300
Marfan Syndrome	650	49
Early Repolarization Syndrome (ERS)	422,484	32,499
Long QT Syndrome (LQTS)	1,625	No data available
Short QT Syndrome (SQTS)	3,250	650
Brugada Syndrome (BrS)	1,625	325
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	650	325
Anomalous Aortic Origin of Coronary Artery (AAOCA)	32,499	3,250
Congenital Heart Disease (CHD)	33,311	22,424
Total Population Estimated to be impacted with Cardiac Diseases in Utah	**526,968**	**67,971**

*The cardiac disease prevalence for UT was estimated by multiplying the national prevalence of each disorder and
the population of the state of UT. Prevalence values are based on the known and diagnosed cases. The number of people
who are undiagnosed could be slightly higher.

Table 4: Cardiac Health - Spectrum of Diseases - Prevalence per State Senator's District in Utah*

	Approximate Prevalence Ranges within Each UT State Senator's Region	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	560	224
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	56	22
Dilated Cardiomyopathy (DCM)	448	45
Marfan Syndrome	22	2
Early Repolarization Syndrome (ERS)	14,568	1,121
Long QT Syndrome (LQTS)	56	No data available
Short QT Syndrome (SQTS)	112	22
Brugada Syndrome (BrS)	56	11
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	22	11
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1,121	112
Congenital Heart Disease (CHD)	1,149	773
Total Population Estimated to be impacted with Cardiac Diseases at Each State Senator's District	**18,171**	**2,344**

*The cardiac disease prevalence for each District in UT was estimated by multiplying the national prevalence of each disorder, and the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Table 5: Cardiac Health - Spectrum of Diseases - Prevalence per House Representative's District in Utah*

	Approximate Prevalence Ranges within Each UT House Representative's District	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	217	87
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	22	9
Dilated Cardiomyopathy (DCM)	173	17
Marfan Syndrome	9	1
Early Repolarization Syndrome (ERS)	5,633	433
Long QT Syndrome (LQTS)	22	No data available
Short QT Syndrome (SQTS)	43	9
Brugada Syndrome (BrS)	22	4
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	9	4
Anomalous Aortic Origin of Coronary Artery (AAOCA)	433	43
Congenital Heart Disease (CHD)	444	299
Total Population Estimated to be impacted with Cardiac Diseases at Each House Representative's District	**7,026**	**906**

*The cardiac disease prevalence for each House Representative's District in UT was estimated by multiplying the national prevalence of each disorder, and by the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Virginia State Demographics and Prevalence Data

Table 1: Virginia (VA) State Demographics

Total State Population[1]	8,001,024
Number of Senators[2]	40
Population per Senator[3]	200,026
Number of House Delegates[4]	98
Population per House Delegate[5]	81,643
Pediatric Population Percentages (%) (<18 years of age)[6]	21.7
Pediatric Population Calculated (<18 years of age)[7]	1,736,222

Source:
[1]Population Data - SC-EST2020-18+POP-RES: Estimates of the Total Resident Population and Resident Population Age 18 Years and Older for the United States, States, the District of Columbia, and Puerto Rico: July 1, 2020. U.S. Census Bureau, Population Division; Release Date: December 2020, Updated May 2021 with Puerto Rico Estimates
[2] https://ballotpedia.org/Virginia_state_legislative_districts#Senate
[3] Population per Senator is a calculated number. The formula used is (Total State Population/Number of Senators)
[4] https://ballotpedia.org/Virginia_state_legislative_districts#House
[5] Population per House Delegate is a calculated number. The formula used is (Total State Population/Number of House Delegates)
[6] SC-EST2020-18+POP-RES
[7] Pediatric Population is calculated number. The formula used is (Pediatric Population Percentages provided in the SC-EST2020-18+POP-RES file multiplied by the State Population).

Table 2: Cardiac Health - Spectrum of Diseases - Prevalence in USA

Disease Type	PREVALENCE RANGES	
	Adult & Pediatric Patients (High End of the Range)	Adult & Pediatric Patients (Low End of the Range)
Hypertrophic Cardiomyopathy (HCM)	0.50%	0.20%
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	0.05%	0.02%
Dilated Cardiomyopathy (DCM)	0.40%	0.04%
Marfan Syndrome	0.02%	0.00%
Early Repolarization Syndrome (ERS)	13.00%	1.00%
Long QT Syndrome (LQTS)	0.05%	No data available
Short QT Syndrome (SQTS)	0.10%	0.02%
Brugada Syndrome (BrS)	0.05%	0.01%
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	0.02%	0.01%
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1.00%	0.10%
Congenital Heart Disease (CHD)	1.03%	0.69%

Source: Cardiac Health - Spectrum of Diseases Prevalence Data & Sources

Table 3: Cardiac Health - Spectrum of Diseases - Prevalence in Virginia*

	Prevalence Ranges by Total Population in VA	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	40,005	16,002
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	4,001	1,600
Dilated Cardiomyopathy (DCM)	32,004	3,200
Marfan Syndrome	1,600	120
Early Repolarization Syndrome (ERS)	1,040,133	80,010
Long QT Syndrome (LQTS)	4,001	No data available
Short QT Syndrome (SQTS)	8,001	1,600
Brugada Syndrome (BrS)	4,001	800
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	1,600	800
Anomalous Aortic Origin of Coronary Artery (AAOCA)	80,010	8,001
Congenital Heart Disease (CHD)	82,010	55,207
Total Population Estimated to be impacted with Cardiac Diseases in Virginia	**1,297,366**	**167,341**

*The cardiac disease prevalence for VA was estimated by multiplying the national prevalence of each disorder and
the population of the state of VA. Prevalence values are based on the known and diagnosed cases. The number of people
who are undiagnosed could be slightly higher.

Table 4: Cardiac Health - Spectrum of Diseases - Prevalence per State Senator's District in Virginia*

	Approximate Prevalence Ranges within Each VA State Senator's Region	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	1,000	400
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	100	40
Dilated Cardiomyopathy (DCM)	800	80
Marfan Syndrome	40	3
Early Repolarization Syndrome (ERS)	26,003	2,000
Long QT Syndrome (LQTS)	100	No data available
Short QT Syndrome (SQTS)	200	40
Brugada Syndrome (BrS)	100	20
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	40	20
Anomalous Aortic Origin of Coronary Artery (AAOCA)	2,000	200
Congenital Heart Disease (CHD)	2,050	1,380
Total Population Estimated to be impacted with Cardiac Diseases at Each State Senator's District	**32,434**	**4,184**

*The cardiac disease prevalence for each District in VA was estimated by multiplying the national prevalence of each disorder, and the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Table 5: Cardiac Health - Spectrum of Diseases - Prevalence per House Delegate's District in Virginia*

	Approximate Prevalence Ranges within Each VA House Delegate's District	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	408	163
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	41	16
Dilated Cardiomyopathy (DCM)	327	33
Marfan Syndrome	16	1
Early Repolarization Syndrome (ERS)	10,614	816
Long QT Syndrome (LQTS)	41	No data available
Short QT Syndrome (SQTS)	82	16
Brugada Syndrome (BrS)	41	8
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	16	8
Anomalous Aortic Origin of Coronary Artery (AAOCA)	816	82
Congenital Heart Disease (CHD)	837	563
Total Population Estimated to be impacted with Cardiac Diseases at Each House Delegate's District	**13,238**	**1,708**

*The cardiac disease prevalence for each House Delegate's District in VA was estimated by multiplying the national prevalence of each disorder, and by the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Washington State Demographics and Prevalence Data

Table 1: Washington (WA) State Demographics

Total State Population[1]	7,693,612
Number of Senators[2]	49
Population per Senator[3]	157,012
Number of House Representatives[4]	98
Population per House Representative[5]	78,506
Pediatric Population Percentages (%) (<18 years of age)[6]	21.7
Pediatric Population Calculated (<18 years of age)[7]	1,669,514

Source:
[1]Population Data - SC-EST2020-18+POP-RES: Estimates of the Total Resident Population and Resident Population Age 18 Years and Older for the United States, States, the District of Columbia, and Puerto Rico: July 1, 2020. U.S. Census Bureau, Population Division; Release Date: December 2020, Updated May 2021 with Puerto Rico Estimates
[2] https://ballotpedia.org/Washington_state_legislative_districts#Senate
[3] Population per Senator is a calculated number. The formula used is (Total State Population/Number of Senators)
[4] https://ballotpedia.org/Washington_state_legislative_districts#House
[5] Population per House Representative is a calculated number. The formula used is (Total State Population/Number of House Representatives)
[6] SC-EST2020-18+POP-RES
[7] Pediatric Population is calculated number. The formula used is (Pediatric Population Percentages provided in the SC-EST2020-18+POP-RES file multiplied by the State Population).

Table 2: Cardiac Health - Spectrum of Diseases - Prevalence in USA

Disease Type	PREVALENCE RANGES	
	Adult & Pediatric Patients (High End of the Range)	Adult & Pediatric Patients (Low End of the Range)
Hypertrophic Cardiomyopathy (HCM)	0.50%	0.20%
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	0.05%	0.02%
Dilated Cardiomyopathy (DCM)	0.40%	0.04%
Marfan Syndrome	0.02%	0.00%
Early Repolarization Syndrome (ERS)	13.00%	1.00%
Long QT Syndrome (LQTS)	0.05%	No data available
Short QT Syndrome (SQTS)	0.10%	0.02%
Brugada Syndrome (BrS)	0.05%	0.01%
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	0.02%	0.01%
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1.00%	0.10%
Congenital Heart Disease (CHD)	1.03%	0.69%

Source: Cardiac Health - Spectrum of Diseases Prevalence Data & Sources

Table 3: Cardiac Health - Spectrum of Diseases - Prevalence in Washington*

	Prevalence Ranges by Total Population in WA	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	38,468	15,387
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	3,847	1,539
Dilated Cardiomyopathy (DCM)	30,774	3,077
Marfan Syndrome	1,539	115
Early Repolarization Syndrome (ERS)	1,000,170	76,936
Long QT Syndrome (LQTS)	3,847	No data available
Short QT Syndrome (SQTS)	7,694	1,539
Brugada Syndrome (BrS)	3,847	769
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	1,539	769
Anomalous Aortic Origin of Coronary Artery (AAOCA)	76,936	7,694
Congenital Heart Disease (CHD)	78,860	53,086
Total Population Estimated to be impacted with Cardiac Diseases in Washington	**1,247,519**	**160,912**

*The cardiac disease prevalence for WA was estimated by multiplying the national prevalence of each disorder and
the population of the state of WA. Prevalence values are based on the known and diagnosed cases. The number of people
who are undiagnosed could be slightly higher.

Table 4: Cardiac Health - Spectrum of Diseases - Prevalence per State Senator's District in Washington*

	Approximate Prevalence Ranges within Each WA State Senator's Region	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	785	314
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	79	31
Dilated Cardiomyopathy (DCM)	628	63
Marfan Syndrome	31	2
Early Repolarization Syndrome (ERS)	20,412	1,570
Long QT Syndrome (LQTS)	79	No data available
Short QT Syndrome (SQTS)	157	31
Brugada Syndrome (BrS)	79	16
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	31	16
Anomalous Aortic Origin of Coronary Artery (AAOCA)	1,570	157
Congenital Heart Disease (CHD)	1,609	1,083
Total Population Estimated to be impacted with Cardiac Diseases at Each State Senator's District	**25,460**	**3,284**

*The cardiac disease prevalence for each District in WA was estimated by multiplying the national prevalence of each disorder, and the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Table 5: Cardiac Health - Spectrum of Diseases - Prevalence per House Delegate's District in Washington*

	Approximate Prevalence Ranges within Each WA House Representative's District	
Disease Type	Adult & Pediatric Patients (High End)	Adult & Pediatric Patients (Low End)
Hypertrophic Cardiomyopathy (HCM)	393	157
Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)	39	16
Dilated Cardiomyopathy (DCM)	314	31
Marfan Syndrome	16	1
Early Repolarization Syndrome (ERS)	10,206	785
Long QT Syndrome (LQTS)	39	No data available
Short QT Syndrome (SQTS)	79	16
Brugada Syndrome (BrS)	39	8
Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)	16	8
Anomalous Aortic Origin of Coronary Artery (AAOCA)	785	79
Congenital Heart Disease (CHD)	805	542
Total Population Estimated to be impacted with Cardiac Diseases at Each House Representative's District	**12,730**	**1,642**

*The cardiac disease prevalence for each House Delegate's District in WA was estimated by multiplying the national prevalence of each disorder, and by the population of the District. Prevalence values are based on the known and diagnosed cases. The number of people who are undiagnosed could be slightly higher.

Cardiac Health – Spectrum of Diseases - Prevalence Data & Sources

Hypertrophic Cardiomyopathy (HCM)

Hypertrophic cardiomyopathy has a prevalence that ranges from 1 in 200-500 people in the general population.

- Maron, Barry J. "Clinical Course and Management of Hypertrophic Cardiomyopathy." *The New England journal of medicine* vol. 379,7 (2018): 655-668. doi:10.1056/NEJMra1710575
- Semsarian, Christopher et al. "New perspectives on the prevalence of hypertrophic cardiomyopathy." Journal of the American College of Cardiology vol. 65,12 (2015): 1249-1254. doi:10.1016/j.jacc.2015.01.019
- Argulian, Edgar et al. "Misconceptions and Facts About Hypertrophic Cardiomyopathy." The American journal of medicine vol. 129,2 (2016): 148-52. doi:10.1016/j.amjmed.2015.07.035
- McKenna, William J et al. "Classification, Epidemiology, and Global Burden of Cardiomyopathies." Circulation research vol. 121,7 (2017): 722-730. doi:10.1161/CIRCRESAHA.117.309711

Dilated Cardiomyopathy (DCM)

Dilated cardiomyopathy has a prevalence that ranges from 1 in 250-2,500 people in the general population.

- Reichart, D et al. "Dilated cardiomyopathy: from epidemiologic to genetic phenotypes: A translational review of current literature." Journal of internal medicine vol. 286,4 (2019): 362-372. doi:10.1111/joim.12944
- Bozkurt, Biykem et al. "Current Diagnostic and Treatment Strategies for Specific Dilated Cardiomyopathies: A Scientific Statement From the American Heart Association." Circulation vol. 134,23 (2016): e579-e646. doi:10.1161/CIR.0000000000000455
- Stojanovska, Jadranka et al. "Congenital and hereditary causes of sudden cardiac death in young adults: diagnosis, differential diagnosis, and risk stratification." Radiographics : a review publication of the Radiological Society of North America, Inc vol. 33,7 (2013): 1977-2001. doi:10.1148/rg.337125073
- Halliday, Brian P et al. "Personalizing Risk Stratification for Sudden Death in Dilated Cardiomyopathy: The Past, Present, and Future." Circulation vol. 136,2 (2017): 215-231. doi:10.1161/CIRCULATIONAHA.116.027134

Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)

Arrhythmogenic right ventricular cardiomyopathy has a prevalence that ranges from 1 in 2,000-5,000 in the general population.

- Calkins, Hugh et al. "Risk Stratification in Arrhythmogenic Right Ventricular Cardiomyopathy." Circulation vol. 136,21 (2017): 2068-2082. doi:10.1161/CIRCULATIONAHA.117.030792
- Oomen, Ad W G J et al. "Diagnosis of Arrhythmogenic Right Ventricular Cardiomyopathy: Progress

and Pitfalls." Heart, lung & circulation vol. 27,11 (2018): 1310-1317. doi:10.1016/j.hlc.2018.03.023

- McKenna, William J et al. "Classification, Epidemiology, and Global Burden of Cardiomyopathies." Circulation research vol. 121,7 (2017): 722-730. doi:10.1161/CIRCRESAHA.117.30971
- Corrado, Domenico et al. "Arrhythmogenic Right Ventricular Cardiomyopathy." The New England journal of medicine vol. 376,1 (2017): 61-72. doi:10.1056/NEJMra1509267

Marfan Syndrome

Marfan Syndrome has a prevalence that ranges from 1 in 5,000 to 1.5 in 100,000 in the general population.

- Cobben, Jan M et al. "Pectus excavatum and carinatum." European journal of medical genetics vol. 57,8 (2014): 414-7. doi:10.1016/j.ejmg.2014.04.017
- The Marfan Foundation. (2018, October 03). What is Marfan Syndrome? Retrieved June 24, 2020, from https://www.marfan.org/about/marfan
- Meester, Josephina A N et al. "Differences in manifestations of Marfan syndrome, Ehlers-Danlos syndrome, and Loeys-Dietz syndrome." Annals of cardiothoracic surgery vol. 6,6 (2017): 582-594. doi:10.21037/acs.2017.11.03
- Meester, Josephina A N et al. "Differences in manifestations of Marfan syndrome, Ehlers-Danlos syndrome, and Loeys-Dietz syndrome." Annals of cardiothoracic surgery vol. 6,6 (2017): 582-594. doi:10.21037/acs.2017.11.03

Long QT Syndrome (LQTS)

The prevalence of Long QT Syndrome is about 1 in 2,000 in the general population.

- Schwartz, Peter J et al. "Prevalence of the congenital long-QT syndrome." Circulation vol. 120,18 (2009): 1761-7. doi:10.1161/CIRCULATIONAHA.109.863209
- Schwartz, Peter J et al. "Long-QT syndrome: from genetics to management." Circulation. Arrhythmia and electrophysiology vol. 5,4 (2012): 868-77. doi:10.1161/CIRCEP.111.962019
- Mizusawa, Yuka et al. "Genetic and clinical advances in congenital long QT syndrome." Circulation journal : official journal of the Japanese Circulation Society vol. 78,12 (2014): 2827-33. doi:10.1253/circj.cj-14-0905

Brugada Syndrome (BrS)

The prevalence of Brugada Syndrome ranges from 1 in 2,000-10,000 people in the general population.

- Gourraud, Jean-Baptiste et al. "Brugada syndrome: Diagnosis, risk stratification and management." Archives of cardiovascular diseases vol. 110,3 (2017): 188-195. doi:10.1016/j.acvd.2016.09.009

- Vutthikraivit, Wasawat et al. "Worldwide Prevalence of Brugada Syndrome: A Systematic Review and Meta-Analysis." Acta Cardiologica Sinica vol. 34,3 (2018): 267-277. doi:10.6515/ACS.201805_34(3).20180302B
- Brugada, Josep et al. "Present Status of Brugada Syndrome: JACC State-of-the-Art Review." Journal of the American College of Cardiology vol. 72,9 (2018): 1046-1059. doi:10.1016/j.jacc.2018.06.037

- Polovina, Marija M et al. “Brugada syndrome: A general cardiologist's perspective.” European journal of internal medicine vol. 44 (2017): 19-27. doi:10.1016/j.ejim.2017.06.019

Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT)

The prevalence of catecholaminergic polymorphic ventricular tachycardia ranges from 1 in 5,000-10,000 in the general population.

- Lieve, Krystien V et al. “Catecholaminergic Polymorphic Ventricular Tachycardia.” Circulation journal : official journal of the Japanese Circulation Society vol. 80,6 (2016): 1285-91. doi:10.1253/circj.CJ-16-0326
- Pérez-Riera, Andrés R et al. “Catecholaminergic polymorphic ventricular tachycardia, an update.” Annals of noninvasive electrocardiology : the official journal of the International Society for Holter and Noninvasive Electrocardiology, Inc vol. 23,4 (2018): e12512. doi:10.1111/anec.12512
- Imberti, Jacopo F et al. “Clinical Challenges in Catecholaminergic Polymorphic Ventricular Tachycardia.” Heart, lung & circulation vol. 25,8 (2016): 777-83. doi:10.1016/j.hlc.2016.01.012
- Wangüemert Pérez, Fernando et al. “Flecainide Reduces Ventricular Arrhythmias in Patients With Genotype RyR2-positive Catecholaminergic Polymorphic Ventricular Tachycardia.” Revista espanola de cardiologia (English ed.) vol. 71,3 (2018): 185-191. doi:10.1016/j.rec.2017.04.032

Short QT Syndrome (SQTS)

The prevalence of short QT syndrome ranges from about 1 in 1,000-5,000 in the adult population, and is about 1 in 2,000 in the pediatric population.

- Campuzano, Oscar et al. “Recent Advances in Short QT Syndrome.” Frontiers in cardiovascular medicine vol. 5 149. 29 Oct. 2018, doi:10.3389/fcvm.2018.00149
- Guerrier, Karine et al. “Short QT Interval Prevalence and Clinical Outcomes in a Pediatric Population.” Circulation. Arrhythmia and electrophysiology vol. 8,6 (2015): 1460-4. doi:10.1161/CIRCEP.115.003256
- Spartalis, Michael et al. “Electrical storm in an acquired short QT syndrome successfully treated with quinidine.” Clinical case reports vol. 7,8 1617-1618. 23 Jun. 2019, doi:10.1002/ccr3.2282
- El-Battrawy, Ibrahim et al. “Long-Term Follow-Up of Patients With Short QT Syndrome: Clinical Profile and Outcome.” Journal of the American Heart Association vol. 7,23 (2018): e010073. doi:10.1161/JAHA.118.010073

Congenital Heart Disease (CHD)

The prevalence of congenital heart disease ranges from 6.90-10.25 in 1,000 in the general population, and is about 13.11 in 1,000 in the pediatric population.

- van der Linde, Denise et al. “Birth prevalence of congenital heart disease worldwide: a systematic review and meta-analysis.” Journal of the American College of Cardiology vol. 58,21 (2011): 2241-7. doi:10.1016/j.jacc.2011.08.025
- Marelli, Ariane J et al. “Lifetime prevalence of congenital heart disease in the general population from 2000 to 2010.” Circulation vol. 130,9 (2014): 749-56. doi:10.1161/CIRCULATIONAHA.113.008396

- Liu, Yingjuan et al. “Global birth prevalence of congenital heart defects 1970-2017: updated systematic review and meta-analysis of 260 studies.” International journal of epidemiology vol. 48,2 (2019): 455-463. doi:10.1093/ije/dyz009

Early Repolarization Syndrome (ERS)

The prevalence of early repolarization syndrome ranges from 1-13 in 100 people in the general population.

- Biasco, Luigi et al. “Early repolarization: an evolving concept for the past 70 years.” Journal of cardiovascular medicine (Hagerstown, Md.) vol. 17,1 (2016): 4-10. doi:10.2459/JCM.0000000000000276
- Bourier, Felix et al. “Early Repolarization Syndrome: Diagnostic and Therapeutic Approach.” Frontiers in cardiovascular medicine vol. 5 169. 27 Nov. 2018, doi:10.3389/fcvm.2018.0016
- Matta, María Gabriela et al. “Epidemiology of early repolarization pattern in an adult general population.” Acta cardiologica, 1-11. 17 Sep. 2019, doi:10.1080/00015385.2019.1667623

Anomalous Aortic Origin of Coronary Artery (AAOCA)

The prevalence of AAOCA ranges from 1 in 100-1,000 in the general population.

- Brothers, Julie A et al. “Expert consensus guidelines: Anomalous aortic origin of a coronary artery.” The Journal of thoracic and cardiovascular surgery vol. 153,6 (2017): 1440-1457. doi:10.1016/j.jtcvs.2016.06.066
- Carvalho, Brunna Priscylla Américo et al. “Late Diagnosis of Anomalous Aortic Origin of a Coronary Artery from the Inappropriate Sinus of Valsalva during Investigation of Chest Pain.” *Case reports in cardiology* vol. 2018 3879243. 30 Jan. 2018, doi:10.1155/2018/3879243
- Brothers, Julie A et al. “Anomalous aortic origin of a coronary artery with an interarterial course: should family screening be routine?.” Journal of the American College of Cardiology vol. 51,21 (2008): 2062-4. doi:10.1016/j.jacc.2008.01.052

Conclusion

Your active participation with HCMA and engagement in legislative advocacy is essential to further HCMA’s strategic priorities. HCMA supports policies that are targeted for (1) improving heart disease surveillance; (2) protecting against sudden cardiac death; (3) ensuring access to high quality and affordable healthcare; (4) protecting patients from harm; (5) addressing inequity in access to, participation in, and utilization of clinical research and health care systems; (6) funding medical research, (7) supporting family caregivers and (8) improving health and biomedical research.

The HCMA Legislative Advocacy Toolkit provides you with the tools necessary to be effective health policy advocates by exercising your rights and responsibilities as citizens to advocate at the state and local levels. By sharing your story or volunteering to share the stories of others impacted by HCM, you are representing

many patients and families with HCM who will never get the opportunity to share theirs. Success through policy and advocacy can motivate others to get involved and to use their voices for progress.

We thank you for taking the time to sign up to become a volunteer at HCMA, attending the training, and reviewing and using this and other resources provided by HCMA. We encourage you to involve your family members, friends and colleagues to join you in your efforts and have them become volunteers at HCMA as well to advance awareness on HCM and HCM spectrum diseases with the policymakers.

Good luck in your advocacy endeavors and don't forget to enjoy while exercising your rights and responsibilities as citizens. We will have our voices heard by working together.