From: Julie Russo Hypertrophic Cardiomyopathy Association <julie@4hcm.org>
Sent: Wednesday, February 12, 2025 6:44 PM
To: Rep. McNamara, Joseph M. <Rep-McNamara@rilegislature.gov>
Subject: Rhode Island Legislators - Children's Cardiac Safety Act Legislative Briefing Recording Now Available

Hypertrophic Cardiomyopathy Association®

Serving the HCM Spectrum Disorder Community Since 19

In case you missed it, the recording of the HCMA's Legislative Briefing for the Children's Cardiac Safety Act to inform Rhode Island legislators is now available.

If you missed any of Tuesday's (2/11/25) webinar detailing the importance of the passage of the Children's Cardiac Safety Act in Rhode Island, you can view the recording by clicking the following link: HCMA Rhode Island Legislative Briefing H 5087

Together, we can save the lives of children in Rhode Island and keep families whole. To learn more about this critical legislation, we are happy to answer any questions and provide additional information. Contact Julie Russo, HCMA Legislative Lead, at julie@4hcm.org.

Warm Regards,

Lisa Salberg

Hypertrophic Cardiomyopathy Association

CEO and Founder

Lisa Salberg H5087

Hypertrophic Cardiomyopathy Association®

HYPERTROPHIC CARDIOMYOPATHY

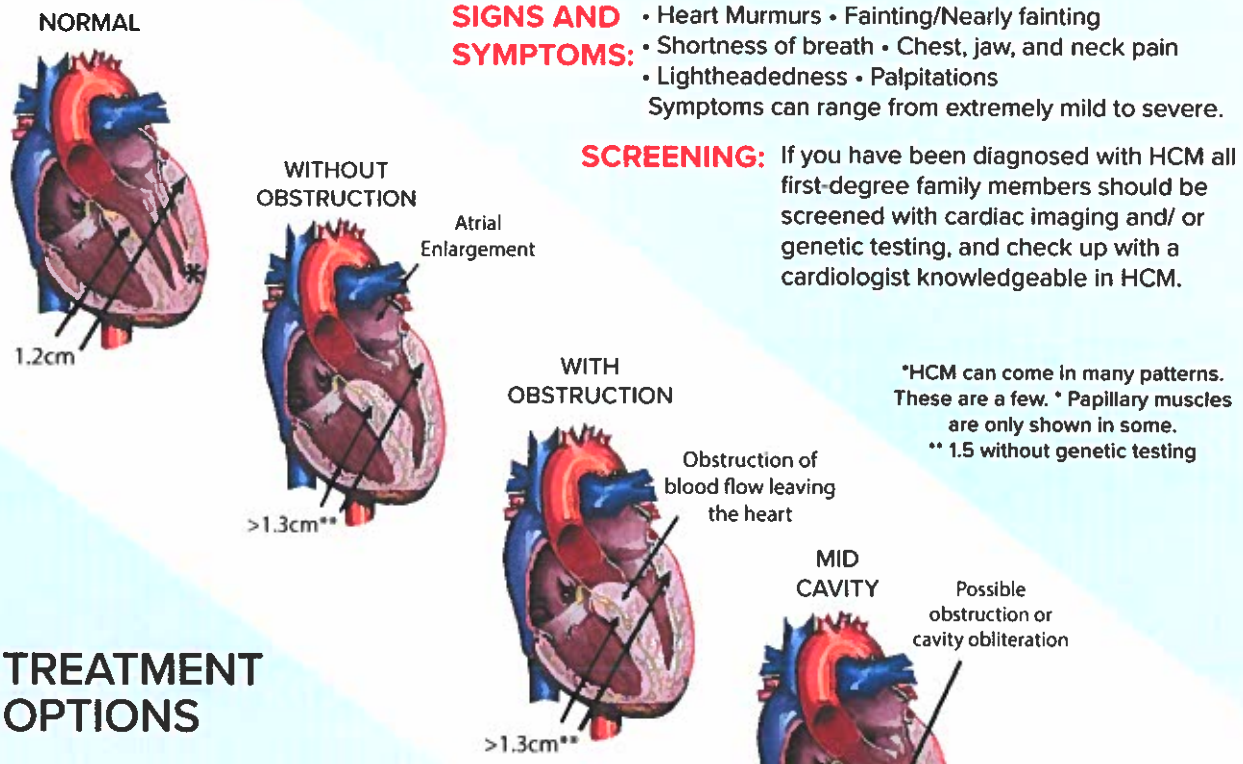
WHAT IS HCM? Hypertrophic Cardiomyopathy (Pronounced: Hyper-trō- fic Cardio-my-opathy) HCM, refers to a family of genetic disorders. HCM causes abnormal cell structure and thickening of the heart muscle. Most commonly, the disease involves abnormalities in genes regulating the cardiac contractile function and less commonly, in other genes which alter the normal functioning of the heart muscle.

HOW COMMON IS HCM? HCM is a relatively common genetic disorder affecting an estimated 1 in 500 worldwide. Recent data suggests it could be as common as 1 in 200.

SIGNS AND SYMPTOMS:
- Heart Murmurs • Fainting/Nearly fainting
- Shortness of breath • Chest, jaw, and neck pain
- Lightheadedness • Palpitations

Symptoms can range from extremely mild to severe.

SCREENING: If you have been diagnosed with HCM all first-degree family members should be screened with cardiac imaging and/ or genetic testing, and check up with a cardiologist knowledgeable in HCM.



*HCM can come in many patterns. These are a few. * Papillary muscles are only shown in some. ** 1.5 without genetic testing

TREATMENT OPTIONS

MEDICATION
- Beta-blockers
- Calcium Channel Blockers
- Myosin Inhibitors
- Norpace/Disopyramide
- Antiarrhythmic drugs
- Diuretics
- Anticoagulants
- Antibiotics
- New medications under investigation
- 90% may require medication

SEPTAL REDUCTION
- Surgery
  >Septal Myectomy
- Nonsurgical
  >Alcohol Septal Ablation
- 20-25% may qualify for septal reduction therapy

RHYTHM MANAGMENT
- Pacemaker
- Implantable Cardioverter Defibrillator
- Atrial Fibrillation Ablation
- 20% may require ICD
- 20% may experience Atrial Fibrillation

TRANSPLANT
- Approximately 3-5% may require a transplant

- Data taken from HCMA database

Hypertrophic Cardiomyopathy Association®

Want to share with your family?

THE HYPERTROPHIC CARDIOMYOPATHY ASSOCIATION:
HOME FOR THE BIGHEARTED
FOR SUPPORT CONTACT:
(973)983-7429 | 4hcm.org | support@4hcm.org