

LMNA and Pediatric Cardiac Disease

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LMNA Patient and Family Day
LMNACardiac and PRIORITY Research Network
The StateView Hotel, Raleigh, NC
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Disclosures

No disclosures, conflicts of interest, or relationships with industry



An Overview

1. What brings families in to be seen?
2. How can *LMNA* variants affect the heart of children and teenagers?
3. How do we evaluate?
4. How do we treat?
5. Can my *LMNA*-variant positive child play sports?
6. Where can I get more information?

What brings families in to be seen?



Fainting with exercise
Awakening without significant confusion

Cascade Genetic Testing from a Family Member



See a Specialist



LMNA Cardiac
Diseases Network

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Find An LMNA Specialist

Search: |

Name	Clinic	Country	State
Dr. Neal Lakdawala	Brigham and Women's Hospital	USA	Massachusetts
Dr. Usha Tedrow	Brigham and Women's Hospital	USA	Massachusetts
Dr. Daniel Jacoby	Yale University Hospital	USA	Connecticut
Dr. John Giudicessi	Mayo Clinic	USA	Minnesota
Dr. Matthew T. Wheeler	Stanford Center for Cardiovascular Diseases	USA	California
Dr. Euan Ashley	Stanford Center for Cardiovascular Diseases	USA	California

Resources

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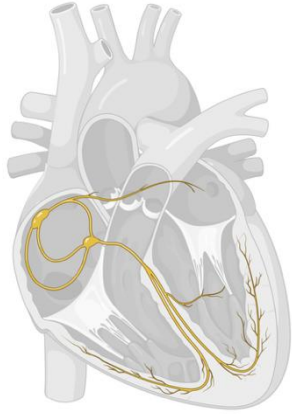
<https://www.lmnacardiac.org/medical-providers/>

**How can *LMNA* variants affect the heart
of children and teenagers?**

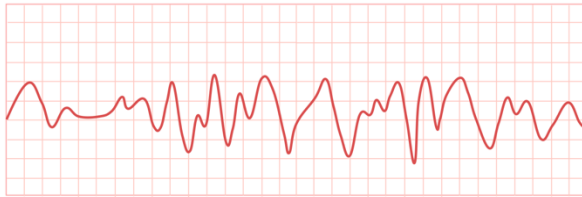
How do we evaluate?

How do we treat?

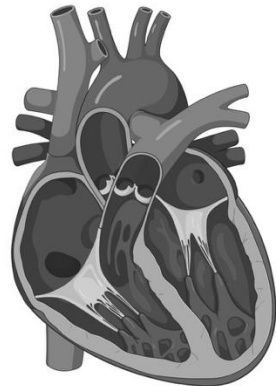
***LMNA* Cardiac Disease in Children and Teenagers**



Conduction System

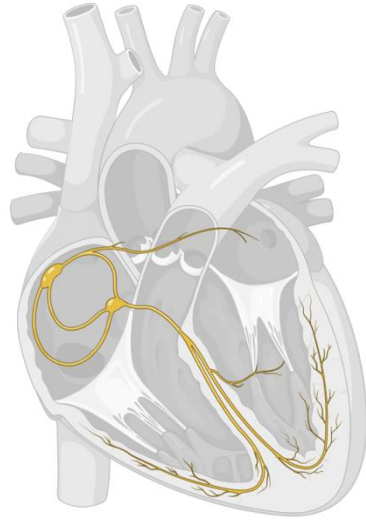


Arrhythmias



Dilated Cardiomyopathy/Heart Failure

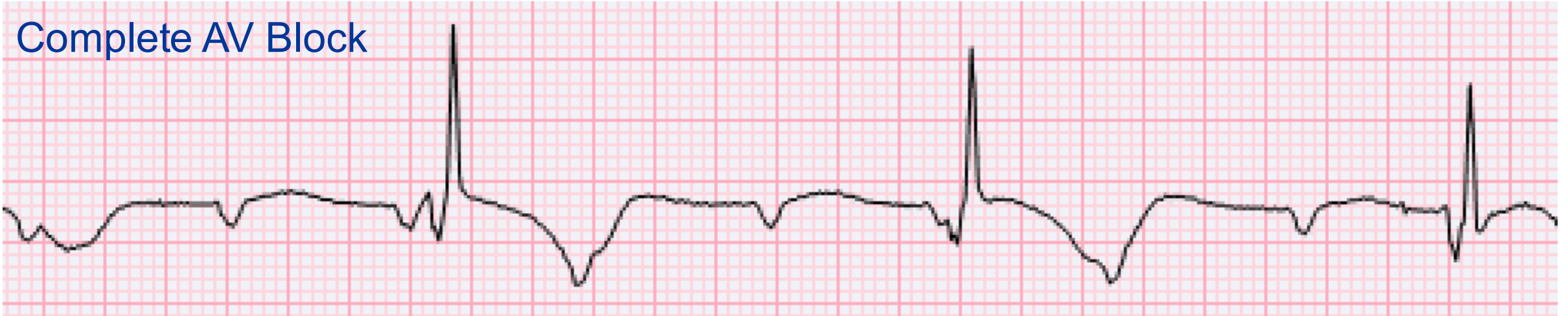
Conduction System Disease



Symptoms

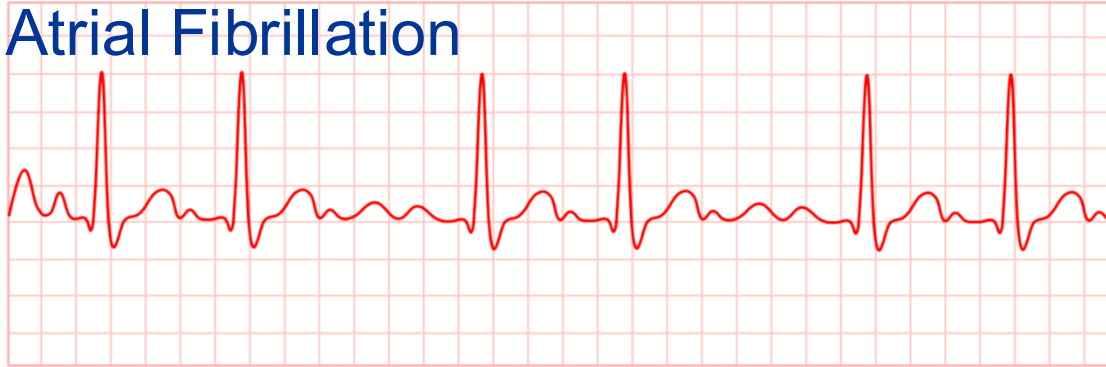
- Tiredness with exercise
- Decreased energy
- Near fainting
- Fainting

Complete AV Block

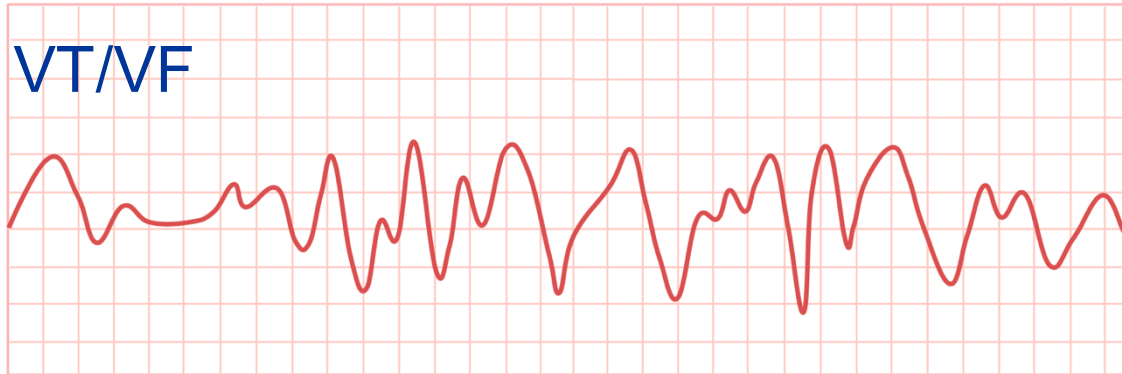


Arrhythmias

Atrial Fibrillation



VT/VF



Symptoms

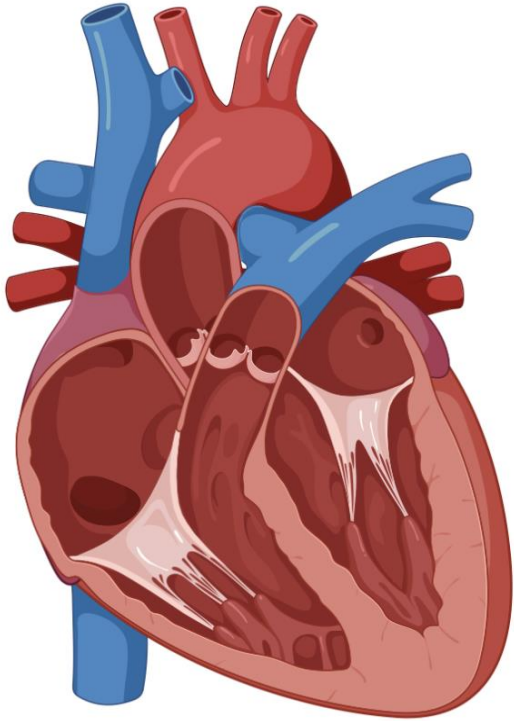
- Palpitations
- Chest pressure
- Shortness of breath
- Near fainting
- Fainting



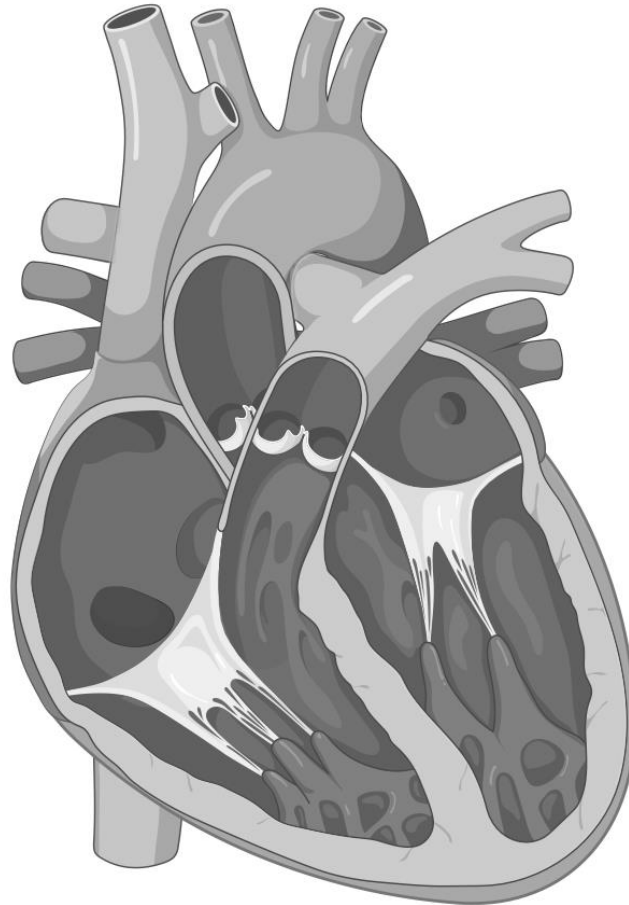


gettyimages®
Credit: ArtMarie

Cardiomyopathies/Heart Failure



Normal



Dilated cardiomyopathy
(Arrhythmic cardiomyopathy)

Symptoms

- Chest pressure
- Shortness of breath
- Poor appetite
- Abdominal pain with eating
- Weight loss
- Constipation
- Near fainting
- Fainting



Summary of the Evaluation

ECG (every year)

24-hour Holter (every year)

Echocardiogram (every year)

Cardiac MRI (every 3-5 years)

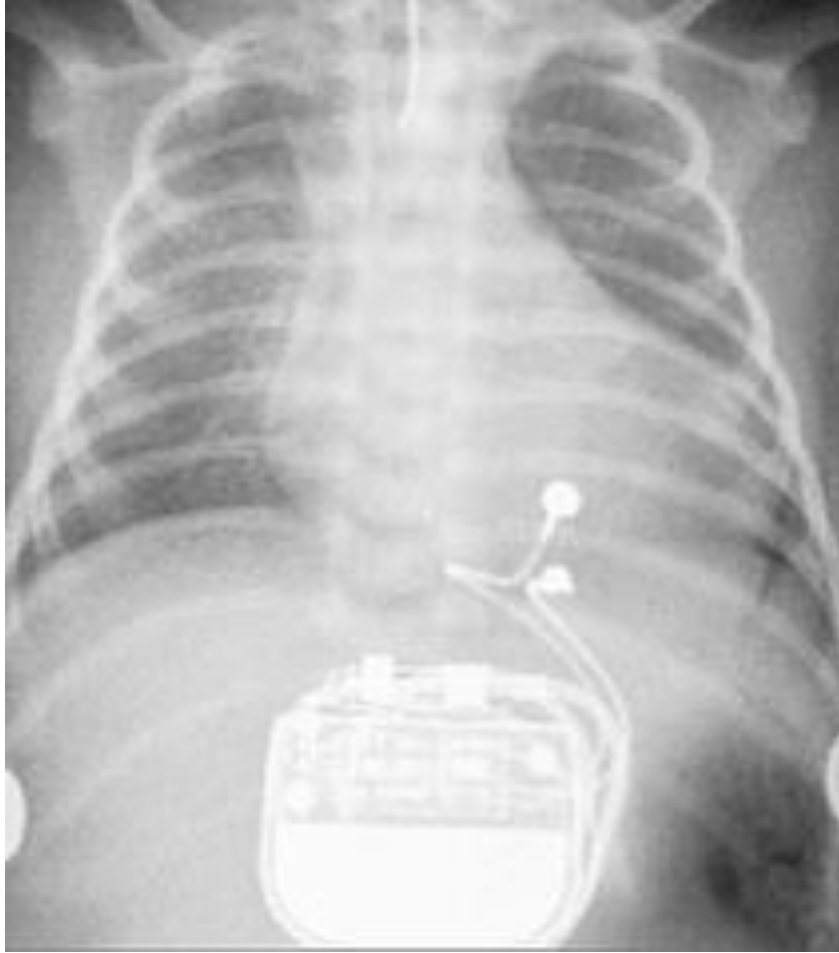
Cardiac Stress Test (every year if playing sports)

Genetic Testing (first visit, then cascade testing of the family)

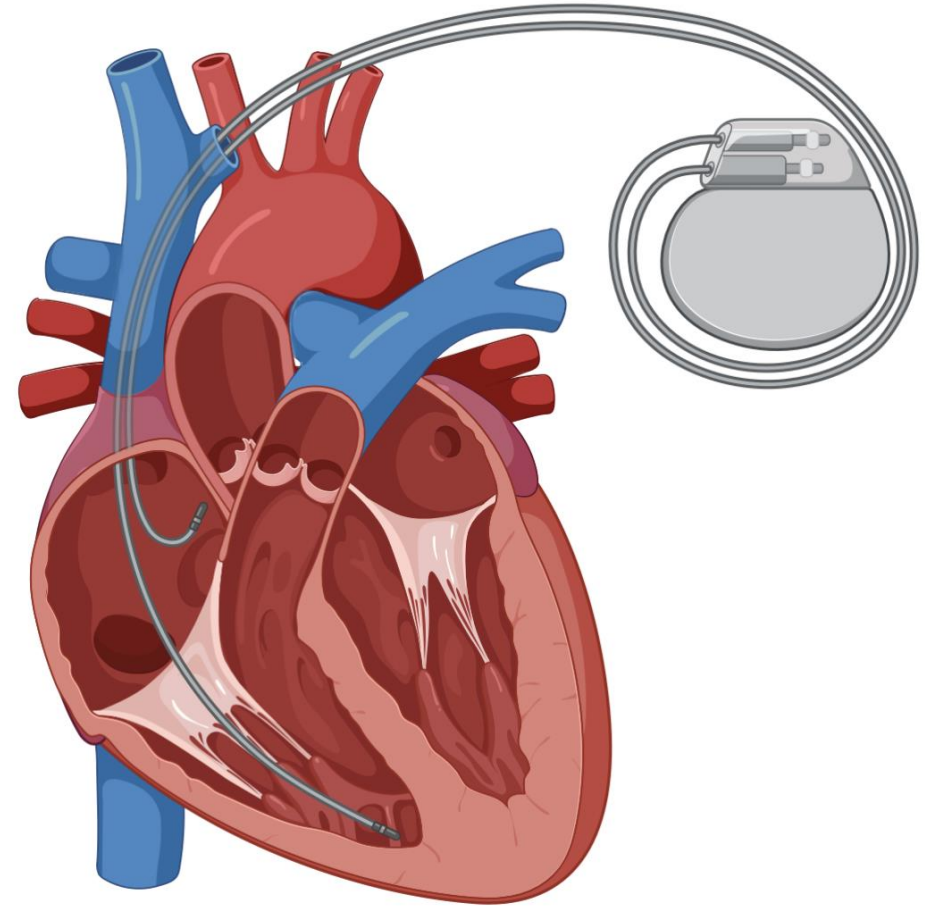
Cardiac Labs: Troponin, BNP, CK, CK-MB (first visit, every 3-5 years)

Metabolic Labs: electrolytes, liver function tests, lipids, LP(a) (first visit, every 3-5 years)

Treatment of Conduction System Disease



Epicardial



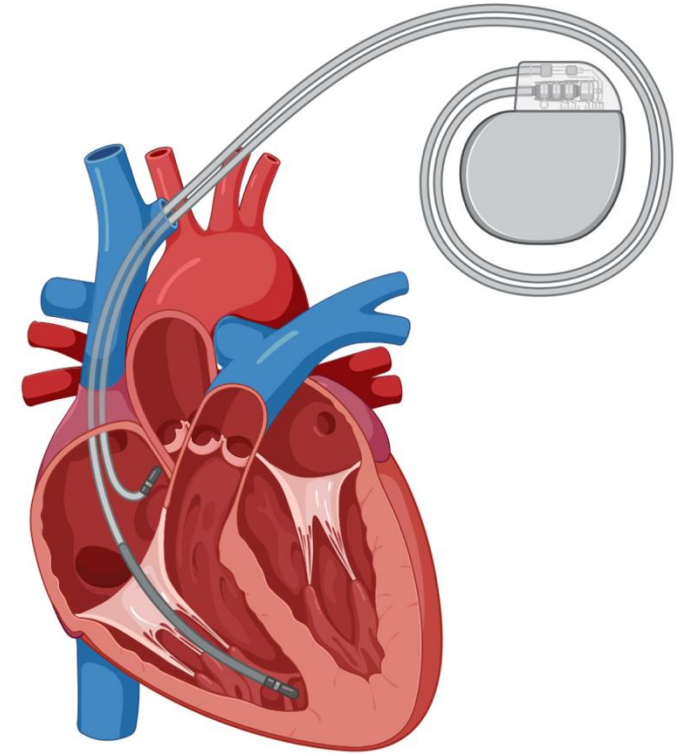
Transvenous

Treatment of Arrhythmias and Cardiomyopathy

Beta blockers (atenolol, metoprolol)
- Can worsen AV block

Anti-arrhythmics (sotalol)
- Avoid amiodarone

ICD placement



Pacemaker/ICD

**Can my *LMNA*-variant positive child
play sports?**

Emergency Action Plan

Cardiac Emergency Response Plan

Name of School District

This Cardiac Emergency Response Plan is adopted by (insert name of school/school district) effective (insert date). This plan was reviewed and approved by medical and legal counsel for (insert name of school/school district) on (insert date).

A cardiac emergency requires immediate action. Cardiac emergencies may arise as a result of a Sudden Cardiac Arrest (SCA) or a heart attack, but can have other causes. SCA occurs when the electrical impulses of the heart malfunction resulting in sudden death.

Signs of Sudden Cardiac Arrest can include one or more of the following:

- Not moving, unresponsive or unconscious, *or*
- Not breathing normally (i.e., may have irregular breathing, gaspings or gurgling or may not be breathing at all), *or*
- Seizure or convulsion-like activity.

Note: Those who collapse shortly after being struck in the chest by a firm projectile/direct hit may have SCA from commotio cordis.

The Cardiac Emergency Response Plan of (insert name of school/school district) shall be as follows:

1. Developing a Cardiac Emergency Response Team

- (a) The Cardiac Emergency Response Team shall be comprised of those individuals who have current CPR/AED certification. It will include the school nurse, coaches, and others within the school. It should also include an administrator and office staff who can call 9-1-1 and direct EMS to the location of the SCA.
- (b) Members of the Cardiac Emergency Response Team are identified in the "Cardiac Emergency Response Team" attachment, to be updated yearly and as needed to remain current. One of the members shall be designated as the Cardiac Emergency Response Team Coordinator.
- (c) All members of the Cardiac Emergency Response Team shall receive and maintain nationally recognized training, which includes a certification card with an expiration date of not more than 2 years.
- (d) As many other staff members as reasonably practicable shall receive training.

2. Activation of Cardiac Emergency Response Team during an identified cardiac emergency

- (a) The members of the Cardiac Emergency Response Team shall be notified immediately when a cardiac emergency is suspected.
- (b) The Protocol for responding to a cardiac emergency is described in Section 8 (below) and in the "Protocol for Posting" attachment.

3. Automated external defibrillators (AEDs) – placement and maintenance

VERSION DATE: SEPT. 9, 2015

ALL UPDATED MATERIALS AVAILABLE AT WWW.HEART.ORG/CERP

1



Great Resource for Emergency Action Plan Templates:
<https://sads.org/schools/school-emergency-plans/>

Project ADAM



MENU
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Sudden Cardiac Arrest can
strike anyone at any time.

Is your community prepared?

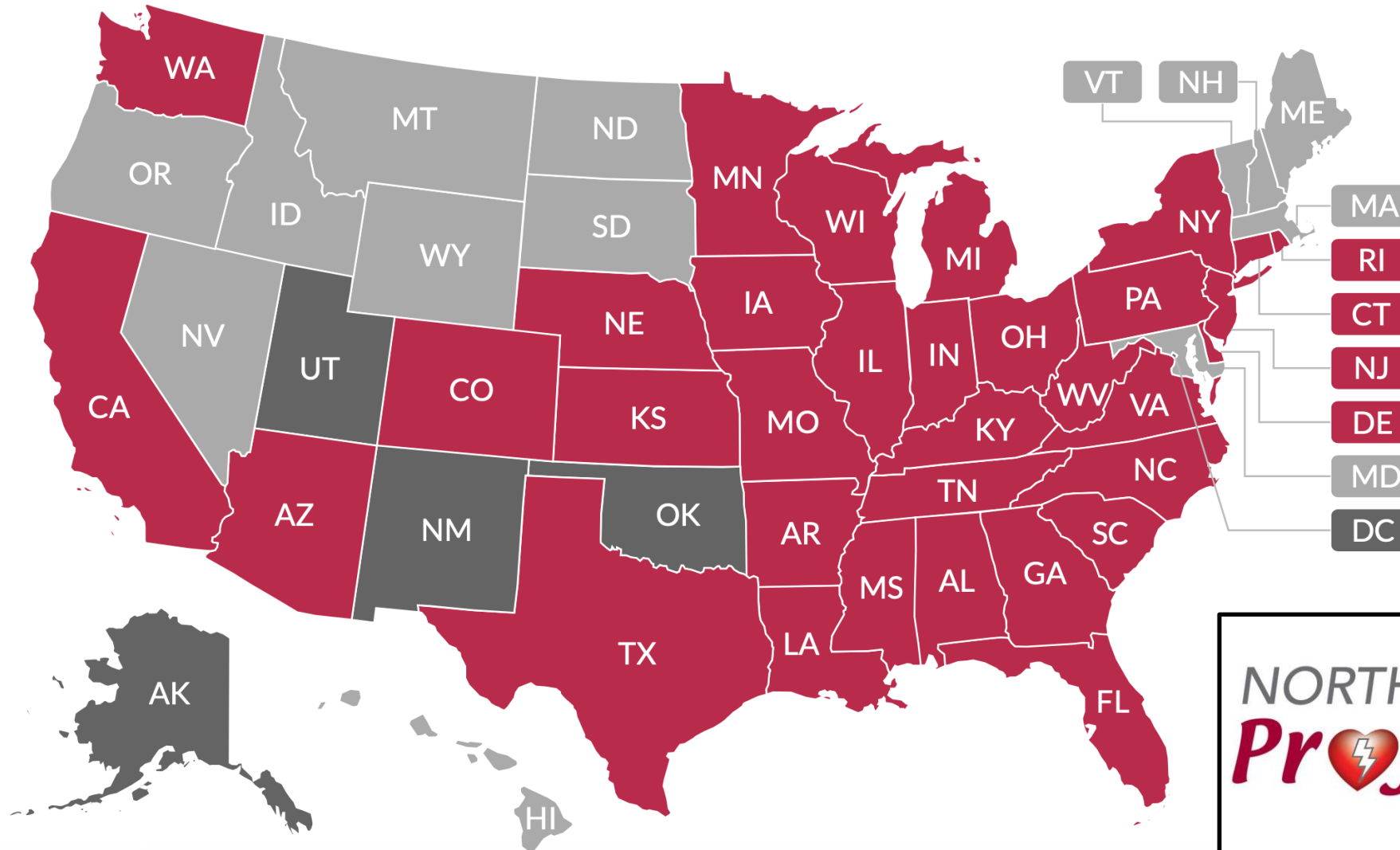


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Connecting People. Accelerating Research.

Our mission is to unite LMNA experts, key opinion leaders, and patients in order to accelerate research and development, aiming to discover an effective treatment for LMNA-related cardiac diseases.



<https://www.lmnacardiac.org>

SADS Foundation



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Supporting Families. Saving Lives.

Our mission is to save the lives and support children, adults, and families affected by genetic heart conditions that predispose them to sudden death due to arrhythmias.



<https://sads.org>

Research Team



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R01-HL149870
R01-EB032726
R01-HL160654
R01-HL166217



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CSDA-2020098



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JOHN TAYLOR BABBITT
FOUNDATION

ADDITIONAL
VENTURES



Duke Precision Genomics Collaboratory

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and Genomics Research Center



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