Find out how we’re Screening Hearts and Saving Lives

Cardiac Arrhythmia Syndromes Foundation

A foundation dedicated to the prevention of Sudden Cardiac Arrest (SCA) through education & awareness initiatives in conjunction with proactive heart screening.

Join us in our mission of proactive prevention

In collaboration we will work together to educate and raise awareness to transform people’s belief that Sudden Cardiac Arrest caused by cardiac arrhythmia syndromes is rare. It is our mission to get the message out that these are serious disease states affecting the adolescent athlete and the young American population all across this country.

In educating the population about the value of preventive heart screenings, we will work to inform the ‘not yet informed’ and to make preventive heart screening available nationwide.

Together we can put an end to Sudden Cardiac Arrest in our youth
Cardiac Arrhythmia Syndromes & Sudden Unexpected Death

Sudden unexpected death (SUD) is defined as “death occurring within one hour of the onset of symptoms in a person without a previously recognized cardiovascular condition that would appear fatal.” Most congenital heart defects and/or arrhythmias that cause sudden death are not generally detected during traditional physical examinations. Under most practice guidelines, patients cannot be referred for cardiac evaluation unless they are symptomatic. However, more than 14,000 young people, especially active ones, succumb to sudden death each year and most display no symptoms or symptoms that are so mild that they are attributed to benign conditions.

In particular, most young athletes at risk of sudden death due to underlying heart conditions never have the opportunity to receive an electrocardiogram (ECG). The preventive heart screenings will go a long way towards solving this problem and identifying those at risk.

**Cardiac Arrhythmia Syndromes (CAS) are also known as:**
- Sudden Unexpected Death Syndrome (SUDS)
- Sudden Adolescent Death Syndrome (SADS)
- Sudden Athletic Death Syndrome (SAD)
- Sudden Infant Death Syndrome (SIDS)
- Long Q-T Syndrome

The leading cardiac arrhythmias accounting for more than 70% of the causes of sudden unexpected death and detectable by ECG screening are:
- Hypertrophic Cardiomyopathy (HCM)
- Arrhythmogenic Right Ventricular Dysplasia
- Myocarditis
- Dilated Cardiomyopathy
- Q-T Segment Prolongation
- Primary Conduction Abnormalities

**Causes of SUD in the Young**

The Leading Cause of Death in Sports

More than 90% of non-traumatic sudden deaths among athletes are related to pre-existing cardiac abnormalities. Young athletes suffer sudden unexpected death at a rate thought to be two to three times greater than their less-active peers because exercise—while not the cause of cardiac defects—can push an already compromised heart over the edge. For example, in August 2005, San Francisco 49ers’ lineman Thomas Herrion looked fine coming off the field after an exhibition game. He entered the locker room and suddenly collapsed. The medical staff responded quickly and Herrion was transported to a local hospital, but it was too late. The 23-year-old was pronounced dead approximately one hour after the game had ended. There have been several high-profile cases of professional athletes dying from cardiac complications:
Hypertrophic Cardiomyopathy (HCM)

The leading cause of sudden unexpected death of people under age 35 is Hypertrophic Cardiomyopathy (HCM). Typically a genetic condition, as are most Cardiac Arrhythmia Syndromes, HCM causes an excessive thickening of the heart muscle, leading to heart rhythm disturbances and sudden death and can often be detected by ECG. Cardiac Arrhythmia Syndromes including HCM are more common in the United States than childhood leukemia, cystic fibrosis, Parkinson’s disease, and multiple sclerosis combine. Each month, 600 young Americans die suddenly and unexpectedly from Cardiac Arrhythmia Syndromes.

Electrocardiography (ECG) vs. Echocardiography

The International Olympic Committee and the European Society of Cardiology have both endorsed the 12-lead ECG as a component of the pre-participation sports evaluation. For large population screenings, non-invasive ECG testing has been recommended over echocardiography as a more effective and cost-efficient screen for cardiac abnormalities. Once a cardiac abnormality has been detected via ECG screening, echocardiography and more invasive testing methods (including genetic testing) are used to diagnose the specific condition. Echocardiography is not a cost-efficient large-pululation screening tool at this time.

ECG screening allows us to detect:
- Abnormalities of the rate and rhythm mechanism of the heart (arrhythmia)
- Evidence of increased thickness of the heart muscle (hypertrophy)
- Signs of acutely impaired or insufficient blood flow to the heart muscle, evidence of a new or previous injury to the heart (e.g. heart attack)
- Signs of inflammation of the sac surrounding the heart (pericarditis).

Legislative Action

Sudden unexpected death has received political attention at the federal level. In 2005 U.S. Representative Carolyn McCarthy (D-NY) sponsored a bill entitled “The Teague Ryan Act” (H.R. 1252). According to data from the Congressional Research Service, the proposed Act stated that, “Each month 600 young people in the United States die suddenly and unexpectedly from cardiac arrhythmia syndromes.” The Act proposed to appropriate $20 million for grants to the states through The Center for Disease Control to fund heart screenings for children and adolescents. Similar bills have been introduced in Congress. Meanwhile, the state of Texas issued an RFP for a 16-month pilot program to provide heart screenings for up to 10,000 6th grade students.

Fast Facts on Cardiac Arrhythmia Syndromes and SCA

- 20 children between the ages of 6 & 25 will die today from sudden cardiac arrest caused by a cardiac arrhythmia syndrome.¹

- 1 out of every 350 children has a cardiac arrhythmia syndrome.²

- 1 out of every 500 children has hypertrophic cardiomyopathy (HCM) the leading cause of sudden death in all young people.²

- Two thirds of SCA deaths occur in people without any prior indications of heart disease.³

- The sensitivity of ECG for hypertrophic cardiomyopathy capable of causing sudden unexpected death in a young athlete is 95%.⁴

- Sudden Unexpected Death is three times more prevalent in young athletes than non-athletes.⁵

- African Americans are more likely to have a SCA than Caucasians and have less than a 1 percent chance of surviving, versus a 5 percent chance in the general population.⁶

- Cardiac arrhythmia syndromes are genetic and hereditary.⁷

- Once a cardiac arrhythmia syndrome is detected and 1st and 2nd degree family members are tested, an average of nine additional cases are found.⁷

- Once diagnosed, these syndromes are treatable, and individuals with these conditions can have normal life spans and lifestyles.⁸

- A defibrillator must be used within 4 minutes of someone having a coronary episode in order to save their life. For every minute that passes without defibrillation, a person’s chances of survival decrease by 10%.⁹

- 95.6% of all Major League Sports Teams require preventive heart screening including an ECG. Less than 14% of all Major League Sports Teams require an echocardiogram.¹⁰

- The 12-lead ECG is the most cost effective pre-participation cardiovascular modality of the three currently recommended methods. Similar cost effectiveness for history and physical examination or 2D echocardiography would require respectively a 2-fold increase in sensitivity or 4.5-fold decrease in cost.¹¹

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¹ Heart Rhythm Society, www.hrsonline.org
² The Teague Ryan Sudden Child Cardiac Arrhythmia Syndromes Screening and Education Act of 2005
³ National Heart Lung and Blood Institute, www.nhlbi.nih.gov
⁴ Fuller, C.M, MD. "Physical examinations for young athletes," Cleveland Clinic Journal of Medicine, March 2005
⁵ International Olympic Committee report noted in Wall Street Journal Article, "Passing Out" When Fainting Signals a Heart Problem," November 8, 2005
⁶ New England Journal of Medicine, content.nejm.org
⁷ American Heart Association, "Testing relatives of young sudden cardiac death victims may reveal others at risk" July 5, 2005
⁸ The Teague Ryan Sudden Child Cardiac Arrhythmia Syndromes Screening and Education Act of 2005
What’s being said in the field

- “1 in 500 people have hypertrophic cardiomyopathy, the leading cause of sudden death in young athletes; most have no idea they are afflicted. A screening electrocardiogram can often identify this as well as other life-threatening conditions. Thus the ECG has the potential to save not only the life of the athlete, but also to alert family members who may be in danger.”

  Sylvan L. Weinberg, MD, MACC, FESC  |  Clinical Professor of Medicine, Wright State University School of Medicine, and Past President of the American College of Cardiology

- “The majority of instances of sudden death in sports are due to a preexisting condition, most of which can’t be recognized on a physical exam, but many of which can be detected with an ECG.”

  Richard Lewis, MD, FACC  |  Former Professor of Medicine, Ohio State University School of Medicine, and Past President of the American College of Cardiology

- “Sudden cardiac death in athletes nearly always has a totally unsuspected genetic or familial basis, but is preventable through discovery by screening, including tests like electrocardiography as offered to parents and schools at community screening events.”

  David H. Spodick, MD, DSc, FACC, MACP, FCCP, FAHA  |  Professor of Medicine, University of Massachusetts Medical School

- "Sudden death in young athletes due to heart disease is an important public health problem. Screening large athlete populations for heart disease carries with it the potential for preventing these tragedies. However, the large population athlete screening process is deceptively complex. It is our clear aspiration that .......... will become a model for such efforts throughout the country and in the process will in fact save lives."

  Barry J. Maron, MD  |  Director of the Hypertrophic Cardiomyopathy Center at the Minneapolis Heart Institute Foundation

A Global Initiative

- The International Olympic Committee requires preventive heart screening of all its athletes in accordance with the Lausanne Recommendations.

- In Italy, an ECG is required (legally mandated) and they have reduced the occurrence of sudden cardiac death in the last 25 years by 89% among athletes.

- In Japan all adolescents receive an electrocardiogram in 1st, 7th, and 10th grades. All adults (> 18) are required to have an electrocardiogram every 2 years.

- Sweden & Iceland have begun screening various demographic populations in accordance with the Lausanne Recommendations.

- The European Society of Cardiology published a consensus report in the European Heart Journal, endorsing a similar proposal (the Lausanne Recommendations) that recommends that every young athlete involved in organized sport has a rigorous physical examination, a detailed investigation of their personal and family medical history and, most importantly a 12-lead ECG. The physician group believes that screening using ECG has the potential to cut sports-related cardiac deaths in Europe by 50%-70% if it can be implemented in every country.

- Stanford University School of Medicine has begun a voluntary program to conduct advanced routine heart testing of all student athletes. Starting with the entire football team in September 2008, researchers completed elective ECGs, on all 800 of the university’s athletes from golfers to swimmers to cross-country runners.

- Johns Hopkins hosted what is believed to be the largest single-day event to date to screen young athletes in the United States for early signs of life-threatening heart defects.
• Columbia University will become the first school in the nation to conduct preseason heart screenings on its football players. John Reeves, Columbia’s former director of physical education and intercollegiate athletics.

• Simon’s Fund (PHW) (PA), any child enrolled in the Colonial School District will be eligible to receive a free ECG exam. Administered by the cardiology team from The Children’s Hospital of Philadelphia (CHOP).

Institutional Comments

• However, this view [screening with a 12-lead ECG is not prudent and practical] represents a perspective on large-scale national screening programs and is not intended to actively discourage individual local efforts. ...the panel does not arbitrarily oppose volunteer-based athlete screening programs with noninvasive testing performed selectively on a smaller scale in local communities if well designed and prudently implemented.

American Heart Association

• Observational data regarding risk stratification for SCD in HCM at present support testing with ECG,........, in addition to obtaining a personal and family history.

American Heart Association/ American College of Cardiology Foundation/Heart Rhythm Society Scientific Statement on Noninvasive Risk Stratification Techniques for Identifying Patients at Risk for Sudden Cardiac Death

• Clinical screening of first-degree relatives and other family members should be encouraged. Therefore, when a DNA-based diagnosis is not feasible, the recommended clinical strategies for screening family members employ history and physical examination, 12-lead ECG, and two-dimensional echocardiography at annual evaluations during adolescence (12 to 18 years of age).

American College of Cardiology/ European Society of Cardiology Clinical Expert Consensus Document on Hypertrophic Cardiomyopathy

Mobile Screenings

In conjunction with local hospitals and schools, CASF offers access to mobile, direct-to-consumer heart screening services for youth and adults. These safe, non-invasive and affordable heart screenings can detect risks associated with cardiac abnormalities and heart disease associated with Sudden Cardiac Arrest (SCA). The screenings complement a routine physical exam and include standardized personal and family cardiac health histories, taking blood pressure readings, body mass index (BMI) calculations and conducting electrocardiograms (ECG) in accordance with principles (the Lausanne Recommendations) adopted by the International Olympic Committee. Screening events are designed to be available to all, regardless of the ability to pay. The operations are managed from an administrative hub in Andover, Massachusetts. Satellite operations are mobile as are the heart-screening teams. Client registrations are taken online or over the phone prior to scheduled screening events. Individual screenings typically take 12 minutes or less to complete. The screening model is unique in that it first targets middle and high school student athletes, now seen as an underserved class of the population. The ECG screening are effective in detecting heart abnormalities as well as affordable for all. CASF partners with other foundations, businesses and community organizations to organize and underwrite the cost of screenings.
Once it has been determined that a group would like to partner with the Cardica Arrhythmia Syndromes Foundation to host a heart screening event and awareness campaign there are a number of things that occur prior to the event.

The CASF is responsible for the creation of all educational and marketing materials. Standard materials produced are posters, flyers, press releases, newsletter or email announcements and Connect-Ed voicemail scripts. CASF produces these items while it is the responsibility of the event partner to distribute the information to their population. As the word is getting out to the community about the issue and the event, required pre-registration is open online and over the phone.

**Below are the steps of a screening from inception to completion:**

1. Registration for a screening can either be done online or by telephone and is required prior to the screening event. During the registration process, the client is asked to complete a questionnaire covering their personal and family cardiac health history and sign a consent form.

2. Prior to the screening, the client’s data is sent to the secure server system at the screening location. On the screening day, the client arrives at the screening center at their chosen appointment time. The client is asked to arrive approximately 10 minutes early. The entire screening takes approximately 12 minutes.

3. The team, consisting of a team leader, intake specialist and multiple ECG technicians, arrives at the location and sets up the screening center made up of private screening rooms.

4. Technicians perform the ECG and take pulse and blood pressure readings. If the client is having a cholesterol and glucose test, that sample is the first step taken. The client’s cholesterol and glucose results will be ready by the time the ECG has been completed.

5. State-of-the-art devices electronically interpret the ECG screening results. In the event that the electronic interpretation reveals an imminent risk or emergency the client is advised accordingly and steps are taken to ensure the safety of the individual. The technology allows the technician to “virtually” bring an on-call cardiologist into the screening booth.

6. All ECGs are over-read via a secure web browser by an independent board-certified and age-appropriate cardiologist.

7. The formal screening results are sent to the client within ten business days. Results include a written report and a copy of the ECG tracing. Also included is a definition of each type of result: normal, borderline, abnormal - non-urgent, abnormal - urgent. Clients are urged to share results with their primary care physician.

8. The record is then permanently stored in a secure server for future retrieval online with a username and password.
When was the last time you had an ECG?
More importantly, when was the last time your child had one?

Everyday you take precautions to protect your children...

Have you had their heart screened?

Cardiac Arrhythmia Syndromes Foundation
300 Ballardvale St. Suite 201 Andover, MA 01810
978-474-8008 | www.SafeBeat.org