# Choosing the Right Heart Screening Program





Screening youth for heart conditions is becoming more common around the country. You may have already been approached by organizations that offer a variety of heart screening options, all with very convincing statistics. There are however, major differences that you should be aware of, and important questions you should ask when making the decision of who's program you should use for your organization. The information below was obtained by addressing these very questions and relying on advice from some of the most respected heart programs in the U.S. including Johns Hopkins and Mayo Clinic. So what are the important factors to consider?

## Scope of the problem

Why screen in the first place? We have all heard stories about youth that are seemingly in excellent health, collapsing suddenly, only to later learn it was caused by an unknown heart condition that predisposed them to sudden cardiac arrest (SCA). According to estimates from the American Heart Association, at least one-half million children in the US have some form of cardiac problem; 1 in 100, (excluding high blood pressure) and approximately 9,500 of those children (<18 years old) experience sudden cardiac arrest (SCA) each year in which only 5% survive. Additionally, statistics from the March of Dimes state 40,000 children are born each year with a heart defect, adding to the number of those with heart-related problems.

## What tests should be included with a screening?

**ECG (EKG):** The ECG is a quick and inexpensive test to conduct and is intended to diagnose electrical disorders. Using it for any other purpose can create false positive results leading to unnecessary and expensive additional testing.

**Echocardiogram:** The echo is used to evaluate the structure of the heart including muscle wall thickness, chamber size, valve function, and coronary arteries. It is considered the "Gold Standard" for detecting underlying and unknown genetic and congenital heart diseases. This includes heart muscle wall defects (present in an estimated 25% of the population) and aortic root dimension (Marfan's).

Other screening tests on athletes that include the vascular system are not recommended due to the extremely low (less than .01%) incidence rate.

## Who should be conducting screenings?

Most screening organizations are born out of the loss of a child and operate with the assistance of an adult cardiologists or family physician. Typically, these screenings include electrocardiogram's (EKG) only due to the low per-test cost, capability of identifying some heart disorder's, and ease to perform. Managing the quality of these screenings, however, is very difficult due to the lack of consistent technicians conducting the screenings, (often lay volunteers). EKGs can miss dangerous heart problems no matter how many times it is performed. For those with hypertrophic cardiomyopathy (HCM), a thickening of the heart muscle, and the most common cause of sudden cardiac death, research shows that at least one in 10 kids with HCM will have a normal EKG in a controlled setting. Coronary artery anomalies are the second-most common cause of death in youth and are missed at least 9 out of 10 times with EKG alone. Insist on a professional, medically-directed organization that specializes in youth heart screenings.

## What is the cost of the testing?

In the case of "ECG Only" screenings, costs run between \$25 and \$50. Organizations that offer complete heart evaluations including ECG and Echo, costs typically run between \$150 and \$250. Sometimes the cost of testing is offset by funding from businesses, personal contributions, or non-profits.

There are some organizations that provide cardiac screenings that promote the ability to bill insurance plans and accepting what insurance will pay. They often pile on tests that may not be appropriate by utilizing a health question-naire that allows them fabricate a diagnosis, (symptoms). The problem is, most kids have no symptoms, and even if it is determined to be a covered expense it may be applied to parents deductible and will be their responsibility to pay, typically \$1,500 and up. Parents must also keep in mind that not collecting the amount you owe as determined by your insurance company is considered insurance fraud. Caution should be used when considering one of these programs. It pays to do your research on any organization you are planning to use to make sure they are legitimate.

## So how do you choose the right program?

It all depends on how detailed a screening you want for your kids. As previously discussed, ECG screenings do not assess the entire heart, only the electrical system. Adding echo to the screening process will provide much more comprehensive results. Most parents assume when they sign their child up for a heart screening, the entire heart is being evaluated including heart walls, coronary arteries, valves, etc. for underlying and undetected genetic, congenital, or acquired cardiovascular diseases.

In addition, a statement from The Council for Cardiovascular Disease in the Young, of the American Heart Association (AHA), recognizes the importance of improving the detection of silent cardiovascular disease in children. The AHA suggest the following principles guide screening organizations and deserve careful consideration when picking a screening program:

- Screening programs should be based on sound principles and should not be simply reactive to recent catastrophic events. A successful screening program does extensive planning and has written procedures and protocols.
- Any broad screening strategy should be widely supported and available to all children. The AHA does not
  support screening strategies that are focused only on children who have the financial means to pay, leaving
  socioeconomically disadvantaged youths out of the process. This is especially true because studies suggest
  that certain groups may be at a higher risk of sudden death.
- Screening programs must track their performance. At the very least, screening initiatives should record the proportion of positive screens and what follow-up was recommended. When possible, the collection of data on the follow-up of positive screens and need for additional diagnostic studies is strongly encouraged.
- Pediatric cardiovascular specialists need to be included in strategies because they look at youth cardiac disease differently. Each child's heart is different and should be assessed that way.
- Programs that promote robust screening methods should include Blood Pressure, ECG, and an Echocardiogram. While these programs usually have a higher cost, (usually \$150), the value received is unsurpassed. Adding Echo to the screening process eliminates guessing and potential follow-up testing a misinterpreted ECG
  can cause.
- Programs should maintain electronic medical records and provide a detailed report of test results to the parent and their personal physician. They may even be able to assist with follow-up care guidance if requested.
- Secondary prevention of sudden death with training of cardiopulmonary resuscitation and deployment of automatic external defibrillators must be emphasized and supported by local entities such as school boards or state legislatures.