

Understanding the Importance of a Youth Cardiac Risk Assessment

As parents we complete many kinds of forms on behalf of our kids. But a youth cardiac risk assessment is really a group effort because the most important contributors of information will be your extended family and your child.

Your Family History

Given sudden cardiac arrest (SCA) is often confused with a heart attack or goes undiagnosed entirely, some families are unaware that a loved one who died from a heart condition under the age of 50, or who had an unexplained car accident or drowning, may actually have had a sudden cardiac arrest. It's important to consult with family members about blood relatives who died under these types of conditions. Furthermore, make a note of any living family members who have been treated for a heart condition – even if it was remedied. Some heart conditions are inherited so it's critical to document this family history.

Know the Potential Warning Signs of a Heart Condition

Many parents are often unaware of potential signs of an undiagnosed heart condition.

- racing heart, palpitations or irregular heartbeat
- dizziness or lightheadedness
- fainting or seizure, especially during or right after exercise
- fainting repeatedly or with excitement or startle
- chest pain or discomfort with exercise
- excessive, unexpected fatigue during or after exercise
- excessive shortness of breath during exercise

We've all experienced these symptoms at one time or another. The key is knowing when these symptoms are repetitive, excessive or unusually timed, for example, a racing heart when you're at rest may be abnormal, but could be normal during activity. And remember: fainting is the #1 sign of a potential heart condition, so it's always advised to visit a doctor for a consultation if fainting occurs.

Complete the Form with your Child

Many heart conditions go undiagnosed because the child hasn't ever talked about a problem. Review each warning sign with your child and ask if they've ever experienced that feeling both at rest or when they're active.

The reality is that we live in a very competitive world, and kids are daily encouraged to rise to the challenge. Young people often don't tell adults if they experience symptoms or don't know that it is an abnormal symptom, and parents often urge their kids to play hard. Kids may be frightened, embarrassed or simply unaware that what they are feeling indicates a potentially fatal condition. Athletes (and often their parents) don't want to jeopardize their playing time, so they may also avoid telling parents or coaches in hope that the symptoms will "just go away" on their own. Or, they may think they're just out of shape and need to train harder. The goal is not to exclude kids from sports but to play safely. Kids shouldn't die doing what they love.

External factors may also increase your child's risk factor. For example, "recreational" drugs or substances, such as cocaine, inhalants, diet pills, performance supplements or energy drinks are not heart friendly. Ask your child for an honest account of their use of these substances.

What to Do with a Completed Youth Cardiac Assessment Form

Most importantly, if you answered “Yes” or “Unsure” to any questions, it’s important to contact your child’s doctor immediately. Review the areas of risk you’ve identified and discuss getting a heart screening or formal cardiac evaluation with a pediatric cardiologist. When ordered by your doctor, insurance often covers cardiac testing, however, your doctor does not have to order an EKG for you to get one and pay for it yourself. EKGs can be less than \$100, and there are often clinics or community organizations that provide them for no or low cost. Check the Parent Heart Watch website for heart screening programs by state.

If no risk factors were identified, you should still update and bring this form to your annual well-child checkup or your young athlete’s pre-participation sports physical so it becomes part of their medical record. Because some conditions can develop as young hearts grow, it’s important to do repeated assessments of your child’s risk factors, so plan to review the assessment form annually.

Once you’ve talked with your doctor about any risk factors and test outcomes, communicate your child’s heart history with the rest of your family so they can seek appropriate screening, as some heart conditions are hereditary.

What is a Heart Screening?

A heart screening typically begins with a cardiologists review of your child’s heart history, then an electrocardiogram (EKG or ECG) and could later include an echocardiogram (ECHO), and in some cases stress testing and additional cardiac imaging, such as CT scans or cardiovascular magnetic resonance imaging (cMRI). These tests are quick, painless and noninvasive.

Parent Heart Watch supports interpreting screening data according to the Seattle Criteria for appropriately aged youth.

If Your Child Is Cleared

This is good news! But to be on the safe side, it’s important to remember that conditions can change as young hearts grow. That’s why international guidelines recommend a screening every two years before age 25—or sooner if your child begins to exhibit any symptoms or warning signs.

Remember that knowledge of heart disease is evolving, so the definition of normal and abnormal can also change over time.

If Your Child Is Diagnosed With A Heart Condition

Your doctor will fully inform you of the recommended treatment plans, which could include taking medication, making lifestyle modifications to reduce risk (which sometimes means refraining from competitive sports), surgery to correct the issue, or implantable devices that monitor your heart rhythm.

It’s important to share your child’s treatment plan with school administration, school nurses, coaches or any other leaders of youth programs your child participates in. As a youth caregiver, they must be aware so they can help monitor your child’s condition and take appropriate action in case of a cardiac emergency.

Parent Heart Watch is a community of parents who understand the importance of sudden cardiac arrest prevention. We have a variety of resources that can assist you. For more information, please visit www.ParentHeartWatch.org.



Pediatric Cardiac Risk Assessment Form

Complete this form for each person under the age of 50, including children, periodically during well child visits including neonatal, preschool, before and during middle school, before and during high school, before college and every few years through adulthood. If you answer "Yes" or "Unsure" to any questions, read the back of this form.

Name: _____ Age: _____ Date: _____

Individual History Questions:	Yes	No	Unsure
Has this person fainted or passed out DURING exercise, emotion or startle?			
Has this person fainted or passed out AFTER exercise?			
Has this person had extreme fatigue associated with exercise (different from others of similar age)?			
Has this person ever had unusual or extreme shortness of breath during exercise?			
Has this person ever had discomfort, pain or pressure in his chest during exercise, or complained of his heart "racing or skipping beats"?			
Has a doctor ever told this person they have: <input type="checkbox"/> high blood pressure <input type="checkbox"/> high cholesterol <input type="checkbox"/> a heart murmur or <input type="checkbox"/> a heart infection? (Check which one, if any.)			
Has a doctor ever ordered a test for this person's heart? If yes, what test and when?			
Has this person ever been diagnosed with an unexplained seizure disorder or exercise-induced asthma? If yes, which one and when?			
Has this person ever been diagnosed with any form of heart/cardiovascular disease? If yes, what was the diagnosis?			
Is this person adopted, or was an egg or sperm donor used for conception?			
Family History Questions (think of grandparents, parents, aunts, uncles, cousins and siblings):			
Are there any family members who had a sudden, unexpected, unexplained death before age 50? (including SIDS, car accident, drowning, passing away in their sleep, or other)			
Are there any family members who died suddenly of "heart problems" before age 50?			
Are there any family members who have had unexplained fainting or seizures?			
Are there any family members who are disabled due to "heart problems" under the age of 50?			
Are there <u>any</u> relatives with certain conditions such as:			
Check the appropriate box: <input type="checkbox"/> Hypertrophic cardiomyopathy (HCM) <input type="checkbox"/> Dilated cardiomyopathy (DCM)			
Check the appropriate box: <input type="checkbox"/> Arrhythmogenic right ventricular cardiomyopathy (ARVC), <input type="checkbox"/> Long QT syndrome (LQTS), <input type="checkbox"/> Short QT syndrome, <input type="checkbox"/> Brugada syndrome, <input type="checkbox"/> Catecholaminergic ventricular tachycardia			
Coronary artery atherosclerotic disease (Heart attack, age 50 years or younger)			
Check the appropriate box: <input type="checkbox"/> Aortic rupture or Marfan syndrome <input type="checkbox"/> Ehlers-Danlos syndrome <input type="checkbox"/> Primary pulmonary hypertension <input type="checkbox"/> Congenital deafness (deaf at birth)			
<input type="checkbox"/> Pacemaker or <input type="checkbox"/> implanted cardiac defibrillator (if yes, whom and at what age was it implanted?)			
Other form of heart/cardiovascular disease or mitochondrial disease			
Has anyone in the family had genetic testing for a heart disease? If yes, for what disease? _____ Was a gene mutation found? Circle one: YES/NO			
Explain more about any "yes" answers here:			
Physical Exam from Physician should include: (to be performed by a physician – made available here for the purpose of parent/patient education to ensure all evaluations have been completed)			
Evaluation for heart murmur in both supine and standing position and during valsava			
Femoral pulse			
Brachial artery blood pressure – taken in both arms			
Evaluation for Marfan syndrome stigmata			
<u>Turn form over if you answered "yes" or "unsure" to one or more questions</u>			

This form includes all items suggested in the American Heart Association Recommendations for Preparticipation Screening for Cardiovascular Abnormalities in Competitive Athletes– 2007 Update Circulation 2007:115

For more information, visit www.choa.org/cardiology, email info@kidsheart.com or call 404-256-2593 (800-542-2233).

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If you answered “yes” or “unsure” to one or more questions on this form, you may be wondering what to do next.

Step One – Contact your health care provider, normally your General Physician, Family Practitioner or Pediatrician and discuss the form. Talk about areas of risk you have identified and discuss having a full cardiac exam by a cardiac professional. Some physicians may be comfortable ordering cardiac testing and interpreting the results and some may not, therefore a referral may be needed to a cardiologist.

Step Two – Based upon your insurance provider, either ask your doctor for a referral for a complete cardiac evaluation by a cardiologist or seek the appointment on your own. This appointment should include basic cardiac testing based on the individual's history but normally includes a consult with the cardiologist, an electrocardiogram (ECG), echocardiogram (echo) and in some cases stress testing and additional cardiac imaging such as CT scans or cardiovascular magnetic resonance imaging (cMRI).

Step Three – Communicate your history to the rest of your family so they can seek appropriate screening.

Things you should know about additional testing for sudden cardiac arrest (SCA) risks:

1. Nearly all tests are painless, noninvasive and require no needles.
2. Tests are an evaluation of the heart at that moment in time and things may change over time, therefore you may need to repeat the testing on yourself or your child at intervals throughout life.
3. The knowledge of cardiac diseases that cause sudden cardiac arrest is evolving, and testing may change over time. The definition of normal or abnormal may also change.
4. If you and/or your loved one are found to be at risk for SCA, there are things you can do to help prevent SCA including:
 - a. Taking medication
 - b. Having an implantable cardioverter defibrillator (ICD) implanted (a pacemaker-like device that can provide a lifesaving shock if you experience SCA)
 - c. Making lifestyle modifications to reduce risk (for example, some may need to refrain from *competitive* sports)

Special note: If you answered “unsure” to questions about health history, discuss the details with complete candor with your health care provider. Cases of adoption, egg or sperm donation, or uncertain paternity are areas of specific concern as the health information that may have been available at the time of adoption, donation or last contact with the father may have changed and you may be unaware. We suggest that you err on the side of caution and seek baseline cardiac testing in these cases.

For more information:

Call Sibley Heart Center Cardiology at 404-256-2593 or 800-542-2233

Email info@kidsheart.com

Visit www.choa.org/cardiology to print additional copies.