



## Understanding the Importance of Pediatric Cardiac Risk Assessment

As parents we complete many kinds of forms on behalf of our kids. But a pediatric 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, who had an explained 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. 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. And remember: fainting is the #1 sign of a potential heart condition, so it's always advised to visit a doctor for a consultation.

- 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

### **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, 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 hopes 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, such as cocaine, inhalants, diet pills, performance supplements or excessive 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 Pediatric 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. When ordered by your doctor, insurance often covers cardiac testing, however, if insurance does not cover it, it’s important to get screened on your own. 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 update and bring this form to your annual well-child checkup or your young athlete’s pre-participation sports physical. Because some conditions can develop as young hearts grow, it’s important to do repeated assessments of your child’s risk factors.

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 (no needles).

Parent Heart Watch supports interpreting screening data according to the Seattle Criteria, which is a measurement system that assess young hearts differently from adult hearts.

### **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, coaches or any other leaders of youth program your child participates in. As a youth caregiver, they must be aware so they can help monitor your child’s condition.

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](http://www.ParentHeartWatch.org).



## Pediatric Cardiac Risk Assessment Form

Complete this form 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, contact your health care provider.*

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: high blood pressure high cholesterol a heart murmur or 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?			
<b>Family History Questions (think of grandparents, parents, aunts, uncles, cousins and siblings):</b>			
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?			
<b>Are there <u>any</u> relatives with certain conditions such as:</b>			
Check the appropriate box: Hypertrophic cardiomyopathy (HCM) Dilated cardiomyopathy (DCM)			
Check the appropriate box: Arrhythmogenic right ventricular cardiomyopathy (ARVC), Long QT syndrome (LQTS), Short QT syndrome, Brugada syndrome, Catecholaminergic ventricular tachycardia			
Coronary artery atherosclerotic disease (Heart attack, age 50 years or younger)			
Check the appropriate box: Aortic rupture or Marfan syndrome Ehlers-Danlos syndrome Primary pulmonary hypertension Congenital deafness (deaf at birth)			
Pacemaker or implanted cardiac defibrillator (if yes, whom and at what age was it implanted?)			
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			
<b>Explain more about any "yes" answers here:</b>			
<b>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)</b>			
Evaluation for heart murmur in both supine and standing position and during valsalva			
Femoral pulse			
Brachial artery blood pressure – taken in both arms			
Evaluation for Marfan syndrome stigmata			