



## Position Statement on Screening for Conditions that May Lead to Sudden Cardiac Arrest in Youth

Parent Heart Watch supports the use of carefully organized and implemented electrocardiogram (ECG) screening in youth to better identify those with conditions associated with Sudden Cardiac Arrest.

### Who is susceptible to Sudden Cardiac Arrest (SCA)?

- Physically active young children, adolescents, and competitive athletes are the most susceptible group as two-thirds of SCA in youth occur with activity/exercise.
- High school and college aged athletes are most affected, but all children, not just athletes, can be affected, including infants.
- Males, black athletes, and basketball players are at highest risk.
- In some cases, no precise cause of SCA can be found.

### How common is SCA?

- The precise incidence of SCA in youth is presently unknown due to the lack of a mandatory and systematic *national* registry of SCA/SCD in youth.
- In 2013, the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) announced their collaboration to create a pilot program - *Sudden Death in the Young Registry*. Data collection will begin in early 2015. This collaboration by the NIH and the CDC is essential for the collection of comprehensive data, estimating the incidence of sudden death in infants, children, and young adults, improved death investigations, as well as expanding research and prevention strategies.

### What types of screening can identify conditions that cause SCA?

- One recommendation for cardiac screening in the United States is the preparticipation history and physical examination.
  - There is no evidence that history and physical examination detects youth at risk for or prevents SCA, as many who experience SCA have been screened, but have not had their conditions identified by the method of history and physical examination alone.

- The ECG can detect most of the conditions associated with SCA.
  - The ECG is a screening test, and with some exceptions (WPW, very prolonged LQT), it is not a diagnostic test for the conditions associated with SCA.
  - For the conditions that can be suspected from the ECG, it is abnormal 70-95% of the time, determined by the specific condition.
  - Notable exceptions include abnormal origin of the coronary arteries, Marfan syndrome and CPVT that cannot be suspected from a resting ECG.

### What conditions cause SCA?

- Sudden cardiac arrest (SCA) or sudden cardiac death (SCD) can be caused by cardiac conditions that are often not recognized prior to the SCA.
- In youth, SCA is associated with the following:
  - *Structural or functional abnormalities of the heart muscle* including hypertrophic cardiomyopathy (HCM), arrhythmogenic right ventricular cardiomyopathy (ARVC), dilated cardiomyopathy (DCM), and left-ventricular non-compaction (LVNC).
  - *Abnormalities of the electrical system of the heart* including long QT syndrome (LQTS), Brugada syndrome, Wolff-Parkinson-White syndrome (WPW), or catecholaminergic polymorphic ventricular tachycardia (CPVT).
  - *Coronary artery anomalies* such as anomalous origin of a coronary artery.
  - *Marfan syndrome* and other connective tissue diseases causing dilatation or rupture of the aorta.
  - *Acquired heart disease* such as myocarditis (inflammation or infection in the heart), commotio cordis (caused by a blow (blunt trauma) to the chest), or drug-induced SCA.
  - *Other congenital heart defects.*
  - *Premature atherosclerotic coronary disease* (although this is an uncommon cause in youth).

### How can ECG screening best be accomplished?

- ECG screening should be carefully executed and must include physicians knowledgeable in ECG interpretation in the population being screened, which could include infants, children, adolescents, young adults, or young athletes.
- Those involved in screening must know how to identify conditions associated with SCA and understand the subsequent evaluation required to diagnose these conditions.
  - This evaluation which confirms the diagnosis and determines the treatment plan is a critically important part of the screening process.

- It must be recognized that one screening using an ECG or any other method does not clear the young person for life.
- We recommend subsequent screening for the following:
  - Youth with any symptoms associated with SCA-related conditions.
  - Youth involved in active sports programs or vigorous physical activity, even if it is recreational.
  - Repeat screening after puberty for youth previously screened prior to puberty.
- The best interval for repeated screening is not determined, but a 1-2 year interval is reasonable.
- Best ECG screening practices should address major barriers to implementing ECG screening on a large scale basis including physician manpower and infrastructure considerations, the logistics of adding an ECG to an athletic, well-child or neonatal evaluation, and the costs of the process.
- We encourage community screening programs to use best practices to identify youth with SCA-related conditions.
- As more knowledge is needed on ECG screening, we encourage screening programs to add to the body of knowledge regarding ECG screening by participating in well-conceived research programs to obtain evidence to answer existing questions and concerns.
- Our support of ECG screening is aimed to identify youth at risk for SCA in an effort to prevent SCD.
- We aim to move the debate over ECG screening for conditions associated with SCA to evidence that supports effective screening to prevent sudden cardiac death in youth.

**What additional tests are used for secondary evaluation or to confirm the diagnosis after screening?**

- Echocardiography (ultrasound) is typically used in the evaluation of individuals with an abnormal history, physical examination, and for most with abnormal ECGs.
- Genetic testing can identify an inherited condition that causes SCA and currently is most helpful when the family mutation is known or a specific condition is suspected from clinical events or other testing.
- Other testing may include exercise stress testing, ambulatory ECG monitors, and MRI or CT scans.

*This statement was developed and approved by the Medical Advisory Board of Parent Heart Watch, the national voice protecting youth from sudden cardiac arrest.*

**Other Resources**

Sudden Cardiac Arrest in Youth Fact Sheet