ESSENTIAL ELEMENTS OF SCREENING DATABASE

February 20, 2015
CSRC Think Tank
• Is it worthwhile to find out how many children have undetected heart conditions?

• Is it worthwhile to find out if there is a more effective way to prevent sudden cardiac death or heart disease?

• Is it worthwhile to define “normal” for kids’ hearts?

• Is it worthwhile to encourage curiosity and promote advancement?
STRUCTURAL

• Confidential and Compliant
  – The data must be protected and secure.

• Accessible
  – The data must be accessible to any qualified researcher regardless of affiliation or opinion

• Uniform
  – The data collection must be standardized

• Scaleable
  – The platform must be available to all interested screening organizations.

• Easy
  – The platform must be intuitive for both the families and the screening organizations.
HeartBytes is a national youth cardiac registry of seemingly healthy kids.

Three Components:
• Historical and Familial Data
• Diagnostic Data
• Digital Images (ECG/Echo)
Consent Form For Final Four Weekend Screening - Apr 4, 2015

I, the undersigned, give consent, for my child to voluntarily participate in the Heart Screening hosted by Simon's Fund. The Heart Screening is not a formal clearance for sports participation. Clearance for sports must be obtained from your physician.

The Heart Screening will include a few tests. My child will receive an electrocardiogram (ECG), have his/her blood pressure checked, have height and weight recorded, have a medical history form reviewed, and if required, based on findings, receive an echocardiogram (ECHO).

Part One: Definitions
An electrocardiogram is a non-invasive test that measures the electrical activity of the heart and can detect certain heart abnormalities leading to sudden cardiac death. My child will have twelve stickers placed on his/her chest, arms, and legs. These stickers are connected to wires and the wires are connected to the ECG machine.

An echocardiogram is a non-invasive test that uses sound waves to create a moving picture of the heart that can detect heart abnormalities. This test is only used if the medical team wants to take a closer look at my child’s heart. This test requires a small amount of gel to be placed on my child’s chest.

Part Two: About the Screening
The Heart Screening is administered by licensed healthcare providers, which may include cardiologists, pediatricians, family doctors, technicians and nurses. The ECG and ECHO results are interpreted by cardiologists.

Part Three: My Responsibilities
I agree to complete a medical history form which will be reviewed by the medical team. Many of the conditions that lead to sudden cardiac arrest and death are genetic and have warning signs. Therefore, the information contained in my medical history form is a very critical piece to the screening process. The information that I provide on the accompanying forms will be complete and correct to the best of my knowledge.

Prior to leaving the Heart Screening, I will receive information about my child’s heart. I understand and acknowledge that my child’s heart is growing, and that his/her heart is changing too. As such, the information I receive from the Heart Screening reflects the condition of my child’s heart today. It does not constitute a conclusive diagnosis of my child’s heart health or physical condition.

I will continue to monitor my child’s heart and become familiar with the warning signs and symptoms of sudden cardiac arrest.

The Heart Screening is not intended to replace regular check-ups with my child’s physician. I further understand and acknowledge that as parent/guardian, it is my duty to discuss any abnormal results with my child’s physician as soon as possible and/or follow up with a pediatric cardiologist.

Type your initials to acknowledge your responsibility contained in the paragraph above

Part Four: Medical Research Release
In exchange for my child receiving a free heart screening, I consent to having my child’s medical information, that is obtained during the Heart Screening, be used for research that is intended to reduce sudden cardiac arrest and death in children. This means that my child’s medical history form, ECG report, blood pressure results, height and weight measurements, and ECHO, if available, may be shared with researchers, after the data is de-identified. My child’s identity will remain anonymous, and our personal information will be kept confidential. I authorize Simon’s Fund to release my child’s information for this purpose.

Part Five: Media Release
I grant Simon’s Fund permission to use any photographs, video and/or audio taken of my child during the Heart Screening for the purpose of fulfilling its mission – to raise awareness about sudden cardiac arrest and death in children. I understand that Simon’s Fund will not use the identity of my child only his/her image. I acknowledge and understand that all media, including photographs, videos and recordings are the property of Simon’s Fund. I also grant Simon’s Fund permission to add me to its email list, which will be used to provide me with updates related to this screening and about the organization’s future endeavors. I understand that I can opt out at any time from the emails.
GATHERING HISTORICAL DATA

Student Information
- First Name
- Last Name
- Current School
- Date of Birth
  - Gender
  - Race

Student Address
- Address:
- City: Marlton
- State: New Jersey
- Zip: 08053

Sports History
- How much exercise and physical activity does your child get per week?
- Does your child play sports?

Past Medical History
- Has your child been diagnosed with any of the following?
  - Anemia
  - Anxiety or Depression
  - Asthma
  - Attention Deficit Hyperactivity Disorder (ADHD)
  - Diabetes
  - Hearing Problems
  - High Blood Pressure
  - Kidney Disease
  - Sickle Cell Anemia
  - Sleep Apnea
  - Name of these apply to my child
  - Other
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**Cancelled Appointments**

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SCREENING DAY
VITALS, MURMUR, ECG AND ECHO

**Vitals**
- Blood Pressure (right arm): 160/74
- Blood Pressure (left arm): 96/72
- Height: 5 FT
- Weight: 129 lbs

**Auto-Calculations**
- BMI: 23.60 lbs/ft^2
- BSA: 1.60 m^2

**Murmur**
- Heart Murmur: Yes
- Murmurs Types:
  - Systolic
  - Diastolic
- Changes with Valves

**Electrocardiogram**
- Status:
  - Normal
  - Abnormal
- Findings:
  - Left Atrial Enlargement
  - Left Axis Deviation
  - Left Ventricular Hypertrophy Pattern
  - Mitral Valve Prolapse

**Echocardiogram**
- Finding Description:
  - LV Systolic Dysfunction
  - LV Hypertrophy
  - Aortic Valve Stenosis
  - Mitral Valve Regurgitation

**Save**:
- Vitals
- Echo
Digital images of ECGs and Echos are linked to the student’s EMR using a unique identifier.
HeartBytes data is available to any qualified researcher, regardless of institutional affiliation or opinion.

Applications are submitted online and reviewed by our Independent Review Team.
WHAT’S IN HERE?
TEAMWORK
CONTACT INFO

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