

# SIMON'S Heart

## Simon's Heart Backgrounder

A strategic, business-minded and impactful nonprofit organization

### History

Simon Sudman was a seemingly healthy three-month old baby boy. He smiled on his 47<sup>th</sup> day. He died in his sleep a month later. After being encouraged by their pediatrician to get their hearts checked, Phyllis, Simon's mom, discovered a heart condition called Long QT Syndrome. This condition has been linked to up to 15% of sudden infant deaths (SIDS). It is also one of several conditions that take the lives of thousands of children every year.

### Mission

To save the life of one child . . . and then another, by raising awareness about the warning signs and conditions that lead to sudden cardiac arrest (SCA) and death.

### Goal

Simon's Heart wants to reduce the incidents of sudden cardiac arrest and death in children by changing the cardiac standard of care to include heart screenings, and making AED devices more accessible in places where kids learn and play. Every child gets his/her eyes and ears screened in school. There are smoke detectors and fire alarms in schools. They should be screened for and safe from cardiac events too.

### Strategy

Simon's Heart believes that preventing sudden cardiac arrest (SCA) in children requires a four prong "DIRE" approach. Detection. Innovation. Reaction. Education.

- **Detection.** The best way to prevent sudden cardiac arrest is to discover the condition before it strikes. Working with a network of over 75 cardiologists, Simon's Heart has provided free heart screenings to over 15,000 students around the country. More than 100 students discovered heart conditions. At the screenings, students receive a physical exam, an electrocardiogram (ECG), and some receive an echocardiogram (Echo).
- **Innovation.** There is a void of research and resources around the study of SCA in youth. What is "normal" for a child's heart? How many children have undetected heart conditions? What is the best way to detect and treat heart conditions?

In response, Simon's Heart invested over \$250,000 to develop HeartBytes, a first-of-its-kind youth cardiac registry of seemingly healthy kids. This digital platform gathers medical and family history, murmurs, ECGs and Echos, and makes the de-identified data available for free to qualified researchers

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from any institution. This method of gathering data streamlines the community heart screening process. Simon's Heart also launched a crowdfunding site called GotAED ([www.gotaed.org](http://www.gotaed.org)) that empowers people to acquire AED devices for places where kids learn and play.

- **Reaction.** SCA can strike at any time. As such, youth facilities and schools must have an emergency action plan that includes cardiopulmonary resuscitation (CPR) and an automated external defibrillator (AED). Simon's Heart teaches students about AEDs and CPR at its youth heart screenings, and donates AED devices to facilities in need.
- **Education.** Parents, students and coaches need to know that sudden cardiac arrest isn't just an adult thing. Pediatricians need to appreciate that fainting during exercise is the #1 warning sign of an undetected heart condition. Simon's Heart educates these groups through a variety of initiatives. The **Sudden Cardiac Arrest Prevention Act**, a bill drafted and supported by Simon's Heart has been signed into law in eleven states and is pending in several others. The bill protects student athletes from SCA by educating parents, teachers and coaches about the warning signs. Simon's Heart supported and funded research has been published in the **American Journal of Cardiology** and the **Journal of Community Health**. It produces the **Chain of Survival Relay** every year so that students can compete, have fun and learn the steps required to save the life of someone in cardiac arrest.

### Finances

To date, Simon's Heart has raised over \$2,000,000 through events and corporate sponsorships. Some notable funders are L'Oreal Paris, Philadelphia Eagles, Philadelphia Phillies, Flyers Charities, Independence Blue Cross, Campus Apartments, Cozen O'Connor, Blank Rome and Ardmore Toyota, NAILBA, Colonial Subaru, the Rothenstein Family and Smith Family. The annual operating budget is \$400,000. Simon's Heart hosts two annual fundraisers. **Simon's Soiree** and **Simon Says Golf**.

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