VISION 2030:
ELIMINATE PREVENTABLE DEATHS FROM SUDDEN CARDIAC ARREST IN YOUTH BY 2030

Parent Heart Watch
THE NATIONAL VOICE
PROTECTING YOUTH FROM SUDDEN CARDIAC ARREST

2016 ANNUAL REPORT
Greetings,

As my tenure comes to an end, I reflect on my time with Parent Heart Watch the incredible friends I’ve made, and the milestones we have reached together.

When we ended last year’s annual report, we were celebrating the accomplishments Parent Heart Watch made in the first decade of its existence. Today, I ask you to join me in recognizing all that we achieved and experienced in 2016.

For the past year, our focus has been devoted to two critical enablers - education and collaboration - that will help us realize our vision of eliminating preventable deaths from sudden cardiac arrest in youth by 2030.

To improve key stakeholders’ knowledge of sudden cardiac arrest in youth we redesigned our educational materials. In September we launched a new and mobile website which introduced The Prevention Promise, a compelling call to action and accompanying tool kit for our constituencies.

In the spirit of collaboration, we held our 11th Annual National Conference (renamed Annual Heart to Heart) in Orlando, where local champions from across the nation came together for inspiration and resources that fuel the creation and continuation of community prevention programs. We are proud that attendees described it as “the best conference yet.”

Our partnership with the National Association of School Nurses expanded to include a social media campaign, featuring a blogpost and newsletter blurb, centered around Sudden Cardiac Arrest Awareness Month in October. In addition, the podcast on sudden cardiac arrest in youth was ranked #8 in the K12 Education category on iTunes.

The above initiatives, along with increased national media coverage - a 15-minute segment on 60 Minutes Sports, and a feature on The Today Show – have contributed to a significant increase in the level of engagement on social media and requests for PHW educational materials.

This year, Maureen Legg joined the PHW team as Development and Communications Manager. With her expertise, we refined our messaging and expanded the pursuit of funding and collaborative opportunities.

In closing, I would like to express my sincere gratitude to our Board of Directors, Medical Advisory Board, membership and supporters for their respective roles in forwarding our mission.

By the time you read this, the mantle will have been passed to our new Chair, Scott Stephens. I am confident that Scott’s leadership and diverse skills will enable Parent Heart Watch to thrive for years to come. I have felt truly supported in my time with PHW, and I know that you will embrace Scott as you did me.

Thank you for allowing me the privilege to serve as your Board Chair for nearly a decade.

Martha Lopez-Anderson
PHW Board Chair
For my first act as your new Board Chair, I’d like to acknowledge Martha Lopez-Anderson for her near-decade leadership of Parent Heart Watch. I am honored to have the opportunity to carry on the organization’s mission in Martha’s footsteps. This community has accomplished so much to advance sudden cardiac arrest awareness and I am eager to now lead the charge to eliminate preventable death and disability from SCA in youth.

I became part of Parent Heart Watch in 2012—the year I lost my son, Cody. The foundation we established in his honor—Cody Stephens Go Big or Go Home—truly characterizes my passion to save young lives. From my experience in finding even one student at risk at one of our school heart screenings, to advocating in the Texas UIL and Texas Legislature for mandatory screenings of all student athletes, I recognize the power of the work we all do no matter how big or small the impact.

We are a community that commands attention, again evidenced by the recent 60 Minutes Sports and TODAY Show segments. I want to continue that momentum. Together, we will build a legacy of survival in the name of our children, and all youth ravaged by sudden cardiac arrest.

“If it wasn’t for Parent Heart Watch, Deb and I would’ve floundered in our loss of Josh. They helped us set a direction, preserve his memory and create a legacy. We never would’ve reached out on our own to anyone who lost a child, but now we are part of a life-giving community."

— RALPH THIBODEAU
Josh Thibodeau Helping Hearts Foundation, Holden, MA

Scott P. Stephens
Chair-Elect, PHW Board of Directors
About Parent Heart Watch

Parent Heart Watch was founded in 2005 by four mothers who each lost a seemingly healthy child to sudden cardiac arrest. Early detection, education, awareness and the proper placement of automated external defibrillators (AEDs) may have saved their children’s lives.

Today Parent Heart Watch serves as the national organization that empowers families to move beyond their own circumstances to become champions for change to protect other young lives. It is an organization of parents who have lost a child to SCA, parents who have a child who survived an SCA or is living with a heart condition, young SCA survivors, medical and allied-health professionals and other action-oriented advocates.

OUR MISSION

Parent Heart Watch is the national voice solely dedicated to protecting youth from sudden cardiac arrest (SCA) and preventable sudden cardiac death (SCD). Parent Heart Watch leads and empowers others by sharing information, educating and advocating for change.

OUR VISION

To eliminate preventable deaths and disabilities from sudden cardiac arrest in youth by 2030.
Operation Prevention

Operation Prevention is the overarching Parent Heart Watch program that empowers communities to protect youth from preventable sudden cardiac death. Its comprehensive education and best practice models have inspired the creation of life-saving primary and secondary prevention programs, as well as collaborations with national health and safety organizations impacting hundreds of thousands of youth, parents, educators, athletic directors, coaches and allied health professionals. This national movement is implemented through three central initiatives.

WE CULTIVATE LOCAL CHAMPIONS who create life-saving community programs that drive the groundswell of demand for the prevention of sudden cardiac death in youth.

WE ARCHITECT COLLABORATIONS that convert passive heart safety protocols into proactive prevention strategies in education, sports, and medical communities.

WE EQUIP CAREGIVERS with the knowledge and tools to protect the young hearts with which they are entrusted.
Operation Prevention

TAKE THE PREVENTION PROMISE
A national outreach program designed to engage the public in sudden cardiac arrest prevention through the Take 5 to Stay Alive toolkit that puts a variety of primary and secondary prevention resources at their fingertips.

ANNUAL HEART TO HEART
A collaborative launching pad where local champions come together and find the resources and inspiration to create community prevention programs fueled by the latest medical updates, hands-on learning, best-practice models and empowering fellowship.

CAMPAIGNS
National media and outreach campaigns that raise awareness of the incidence of SCA in youth and increase recognition that SCA can often be prevented, fueled by the distribution of thousands of free or low-cost educational materials throughout the year.
OPERATION PREVENTION

PRIMARY PREVENTION EDUCATION

Education campaigns about primary prevention strategies, such as highlighting the warning signs and risk factors of a heart condition and advocating for early detection through heart screenings with electrocardiograms (ECGs) and echocardiograms.

SECONDARY PREVENTION EDUCATION

Promoting the cardiac chain of survival through widespread availability of properly maintained and accessible automated external defibrillators (AEDs) at all schools, sporting events and youth organizations; critical CPR and AED training, and the importance cardiac emergency response plans (CERP).

MAKE OUR KIDS COUNT:
EVERY YOUTH/EVERY TIME

A database of SCA and SCD in youth occurrences to provide insight as to their true extent as well as survival trends. In the absence of a systematic and mandatory national registry reporting this incidence, PHW contributes this data to efforts that drive change in prevention best practices.
OPERATION PREVENTION

An ongoing effort to support the creation and perpetuation of local primary and secondary prevention programs championed by Parent Heart Watch Members.

CONNECTED BY HEARTS

An education, support and networking initiative for young survivors of sudden cardiac arrest and those living with heart conditions, founded in 2011 by a group of young people who wanted to share their experiences with others navigating their own heart journey.

NATIONAL ADVOCACY

Advocating for SCA prevention in youth in education, sports and medical communities by having a voice at national conferences and participating in and perpetuating national coalitions and partnerships.

COMMUNITY PROGRAMS

An ongoing effort to support the creation and perpetuation of local primary and secondary prevention programs championed by Parent Heart Watch Members.
Highlights of 2016

NEW WEBSITE
Parent Heart Watch launched a newly designed, updated and mobile website to meet the growing demand for information on SCA in youth. The new website highlights the Prevention Promise and accompanying 5 to Stay Alive toolkit, which features five specific action steps that parents and caregivers can take to protect children from sudden cardiac death.

INCREASED MEDIA COVERAGE
From a 20-minute segment on 60 Minutes Sports (“The Heart of an Athlete”) to a showcase piece on NBC’s The Today Show (“Parents Unite to Combat Sudden Cardiac Arrest in Young Athletes”), 2016 was a banner year for media coverage of SCA in youth, resulting in an increase in requests for materials and information on the topic.

NATIONAL COLLABORATIONS
In 2016, Parent Heart Watch partnered with the National Association of School Nurses (NASN) on two key initiatives. The first was a social media campaign during Sudden Cardiac Arrest Awareness Month in October, which reached 46,000 people. PHW Executive Director Michele Snyder was featured on an NASN Radio Podcast (Sudden Cardiac Arrest) and the episode reached the #8 spot in the K-12 education category on iTunes.

The second is a program with Firehouse Subs Public Safety Foundation who granted AEDs to be placed by members, in conjunction with school nurses, at sixteen schools across the country. SCA Awareness Month also featured a partnership with the National Parent Teachers Association which included social media outreach and a blogpost on SCA in Youth.

KEYNOTE PRESENTATIONS
PHW Board Chair Martha Lopez-Anderson served as the keynote speaker at the 2nd Annual Collaborative Solutions for Safety in Sports, hosted by the National Athletic Trainers’ Association and the American Medical Society for Sports Medicine in March 2016.

PUBLICATION OF THE CARDIAC EMERGENCY RESPONSE PLAN (CERP)
The CERP is a written document that establishes specific steps to reduce death from cardiac arrest in school settings. It was developed by a coalition of thirteen SCA advocacy organizations including PHW. The CERP Policy Manuscript was officially released in the September 2016 issue of NASN School Nurses.

EDUCATIONAL MATERIALS
As a result of increased media coverage, Parent Heart Watch updated its educational materials and distributed more than 43,000 in 2016.

CONNECTED BY HEARTS GROWS
Connected By Hearts (CBH), which provides education, support and networking to young survivors of sudden cardiac arrest and those living with heart conditions, showed a marked increase in engagement in 2016. More than 20 new blogs were submitted as a result!
2016 Heroes for Young Hearts Awards

Five remarkable individuals were honored at the 11th Annual National Parent Heart Watch Conference in Orlando, Florida, for their dedication and commitment to saving young lives from SCA.

**LOCAL CHAMPIONS**

**MICHAEL LOIZ**
Connecticut
Advocacy Champion - Medical or Allied Health Professional

**SAMEER JAFRI**
California
Advocacy Champion - Youth

**SCOTT & MELODY STEPHENS**
Texas
Advocacy Champions - Adult

**STEVE TANNENBAUM, ESQ.**
New York
Founders’ Award

**JACK CADIGAN, IV**
Massachusetts
Advocacy Champion - Survivor
**EVERY CHILD. EVERY HEART... BY THE NUMBERS**

1,116,000+
**REACHED VIA SOCIAL MEDIA**

PHW posts the latest news on losses, saves, research studies and more around sudden cardiac arrest in youth.

4,742
**AEDS PLACED TO DATE**

PHW members place AEDs wherever youth congregate.

22,000
**WEBSITE VISITORS**

looking for information about sudden cardiac arrest (SCA) prevention in youth.

430,566
**YOUTH SCREENED TO DATE**

44 member organizations offering free or affordable heart screenings in 24 states, checking hearts with electrocardiograms (ECGs) and echocardiograms to identify kids at risk from underlying heart conditions.

354,339
**TRAINED TO DATE**

CPR + AED to empower them to save a life in the case of a cardiac emergency.

2.1M+
served to date by the AEDs

PHW Members have placed across the country.

43,000+
**EDUCATIONAL MATERIALS**

PHW provides free posters, postcards, brochures, research articles and fact sheets that raise awareness among millions of people.
Sudden Cardiac Death in youth is preventable!

TAKE THE PREVENTION PROMISE

ParentHeartWatch.org

If you could prevent a tragedy from happening, wouldn't you?
Take 5 to Stay Alive

Sudden Cardiac Arrest (SCA) is the #1 killer of student athletes and contributes to the #2 medical cause of death of those under the age of 25. SCA is the leading cause of death on school campuses. The biggest misconception about SCA is that “it just happens” and there’s nothing you can do to stop it. The truth is that sudden cardiac arrest IS preventable — but that doesn’t happen by chance.

*Take the Prevention Promise and learn what you can do to save a young life.*

- **Heart Health History Assessment**
  
  Know your family heart history and ask your child about symptoms that could be warning signs of a heart condition.

- **Engage in Primary & Secondary Prevention**
  
  Heart screenings for early detection of risk factors that may lead to SCA and being prepared for a cardiac emergency saves lives!

- **Advocate in Your School**
  
  Champion widespread, accessible AEDs throughout your campus CPR/AED training for staff and students and Cardiac Emergency Response Plans.

- **Review Cardiac Emergency Response Plan**
  
  Demand life-saving protocol at camps, sports and youth programs. That means AEDs where youth practice & play and SCA training for adults.

- **Talk to Your Doctor**
  
  Make SCA prevention a standard part of regular checkups and sports physicals. Discuss risk factors, warning signs and getting a heart screening.

Visit [ParentHeartWatch.org](http://ParentHeartWatch.org) for your SCA prevention toolkit!
2016 Board of Directors

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Florida

STEWARD KRUG
VICE CHAIR
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RICHARD HELGESON, CPA
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Maryland

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New York

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New York

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STAFF

MICHELE SNYDER
EXECUTIVE DIRECTOR

MAUREEN LEGG
DEVELOPMENT AND COMMUNICATIONS MANAGER
Medical Advisory Board

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*CHAIR*  
Professor of Pediatrics - The Children’s Hospital of Philadelphia, Perelman School of Medicine at the University of Pennsylvania, Director, Youth Heart Watch

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Executive Director, Heart Center, Pediatric Heart Center, Laurie Children’s Hospital, Vice Chair, Clinical Affairs Pediatrics, Laurie Children’s Hospital, Professor of Pediatrics, Northwestern University

**JONATHAN DREZNER, M.D.**  
Associate Professor - Department of Family Medicine, University of Washington, Associate Director - Sports Medicine, Fellowship, University of Washington, Team Physician - Seattle Seahawks and University of Washington Huskies

**STEPHANIE H. FELGOISE, PHD, ABPP**  
Professor and Director - Department of Psychology, Philadelphia College of Osteopathic Medicine

**JOSEPH C. MAREK, M.D.**  
Senior Medical Director - Cardiopulmonary Services, Advocate Medical Group, Founder & Medical Director - Young Hearts for Life™, Cardiac Screening Program
“Parent Heart Watch has long advocated for a national registry that would count all Sudden Cardiac Deaths in youth, to provide evidence that these tragedies are not rare events. The tenacious efforts of members to educate and advocate for a registry influenced heightened federal interest, which led to the 2012 establishment of the Sudden Death in Young Case Registry — a partnership between NIH, the CDC and the National Center for Child Death Review, with Parent Heart Watch represented on the Registry’s Advisory Committee.”

— THERESA COVINGTON, MPH
Executive Director, National Center for the Review and Prevention of Child Deaths
**2016 Financial Report**

**INCOME**

**PUBLIC SUPPORT**

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<tr>
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<th>2016</th>
<th>2015</th>
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<td>Individual Contributions</td>
<td>$74,584</td>
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<td>Foundation Support</td>
<td>$63,275</td>
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<td>Corporate Support</td>
<td>$67,978</td>
<td>$52,950</td>
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<td>Gifts in Kind</td>
<td>Less Contributions, Restricted for future use</td>
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<td><strong>TOTAL PUBLIC SUPPORT</strong></td>
<td>$205,838</td>
<td>$218,646</td>
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**OTHER REVENUE**

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<tr>
<td>Conference Sales &amp; Registration</td>
<td>$28,828</td>
<td>$29,082</td>
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<td>Membership Dues</td>
<td>$6,165</td>
<td>$6,920</td>
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<td>Donated Services</td>
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<td><strong>TOTAL OTHER REVENUE</strong></td>
<td>$36,993</td>
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**EXPENSES**

**PROGRAM SERVICES**

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<td>Annual Conference</td>
<td>$81,027</td>
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<tr>
<td>Education and Outreach</td>
<td>$50,545</td>
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<td>Other Programs</td>
<td>$58,162</td>
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<td><strong>TOTAL PROGRAM SERVICES</strong></td>
<td>$189,734</td>
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**SUPPORTING SERVICES**

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<tr>
<td>Administration</td>
<td>$35,892</td>
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<td>Fundraising</td>
<td>$34,809</td>
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<td><strong>TOTAL SUPPORTING SERVICES</strong></td>
<td>$70,701</td>
<td>$67,494</td>
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**TOTAL PROGRAM AND SUPPORTING SERVICES**

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<th>2015</th>
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<tbody>
<tr>
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<td>$260,435</td>
<td>$263,696</td>
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FY2016 Financials include October 1, 2015 - September 30, 2016
Thank You to Our Donors!

$50,000 AND ABOVE
Susan Fiorelli

$15,000 - $49,999
Boston Scientific Corporation
One Beat CPR + AED

$2,500 - $14,999
Atran Foundation, Inc.
Bryce C. Turner Memorial Foundation, Inc.
Cody Stephens Go Big or Go Home Memorial Foundation, Inc.
Dominic A. Murray 21 Memorial Foundation Inc.
Louis J Acompora Memorial Foundation
Simon’s Fund

$1,000 - $2,499
Adam P. Seymour Foundation, Inc.
Dana Anderson and Martha Lopez-Anderson
John Ehinger
Eric Paredes Save A Life Foundation
Jonathon R. Cowley Memorial Fund
Stewart Krug
Nicholas R. Longo
Norm and Kim Okerstrom
Strata Verve, Inc.
The Adam Frand Foundation
Tommy Schuman Foundation
Ashlee Valavala

$500 - $999
Anthony Bates Foundation
Bernard and Eva Resnick Foundation, Inc.
Arnold and Suzy Cohen

$250 - $499

James Dolan
Richard and Rita Helgeson
Silas Koulacl
Julie Lyksell
Jim Markisohn
Jim McFarland
Daniel Pieroni, MD
Linda Quijano
Andrea Sidorow
Screening America (Transmed, Inc.)
Steven Tannenbaum, Esq.
The Adam L. Thompson Foundation
Ann Thompson
Claudia Vergara
Via Heart Project
Flynn Wurtzbacher

Jim Madaffer
Martha Metacarpa
Rachel Moyer
Kim Namey
Lynn Oill
Charles Oliver
Pfizer Foundation
Patricia Podufalski
Paul and Iris Pollack
Larry and Evelyn Pontbriant
Bonnie Stewart
Mark Stoff
The Travis R. Roy Sudden Cardiac Arrest Fund
Brian Trainor

Under $100
Alan Adelman
Pamela Ajourney
Anna Marie Bonafide
Ahmer Ansari
Peter Antevy
Matthew Castner
Daemon College
Dawna Cornelissen
Dorcas Dillard
Rose Feeney
Laurie Finlayson
Ann Haber
Hawaii Heart Foundation
Gerry Hendrix
Gregory Jackson
Jack Katz
Nicholas Keselowsky
Peter Kessler

Includes donation period of October 1, 2015 - September 30, 2016
National Voice Initiative

The National Voice Initiative is a new effort to insure the sustainability of Parent Heart Watch for future generations. We are grateful to the generous individuals and families who have chosen to make an annual donation from their foundations, over and above their membership dues or personal gift, in recognition of Parent Heart Watch’s role in supporting and amplifying their local work at a national level.

Adam P. Seymour Foundation, Inc.  
Anthony Bates Foundation  
Bryce C. Turner Memorial Foundation, Inc.  
Children’s Cardiomyopathy Foundation  
Cody Stephens Go Big or Go Home Memorial Foundation, Inc.  
Dominic A. Murray 21 Memorial Foundation Inc.  
Eric Paredes Save A Life Foundation  
Hawaii Heart Foundation

Jonathon R. Cowley Memorial Fund  
Louis J. Acompora Memorial Foundation  
Play with Heart Foundation  
Simon’s Fund  
The Adam Frand Foundation  
The Adam L. Thompson Foundation  
The Travis R. Roy Sudden Cardiac Arrest Fund  
Tommy Schuman Foundation  
Via Heart Project
Special Thanks to our Lifetime Legacy Members!

Thank you to our Lifetime Legacy Members who have made a one-time membership payment of $500 or more.

Karen and John Acompora  
Suzanne and Steve Apodaca  
Nancy and A.J. Barcia  
Barbara Bergin-Nader  
Bob and Troy Bowman  
Debbie and Richard Burch  
Susan Canning  
Amy and David Cockrell  
Linda Cotter Forbes  
Theresa Covington  
Linda and Bob Cowley  
Connie and Rich Dahlem  
Linette Derminer  
James Dolan  
Kelly and Scott Driscoll  
Susan and Dave Fiorelli  
Sheila and James Fisher  
Rhonda Foster  
Debbie and Scott Goyne  
Rita and Richard Helgeson  
Paul Kearns  
Stewart Krug  
Liz Lazar  
Maureen Legg  
Cyndie Lempesis  
Brenda Lewis  
Martha Lopez-Anderson and Andy Anderson  
Melinda Murray  
Kim and Norm Okerstrom  
Jose Ortega  
Christine Puricelli  
Gertha Richard  
Bob Roy  
Kim Ruether  
Michael Schoonover  
Correll and Robbie Seidel  
Teresa Sorenson  
Michelle Spencer  
Phyllis and Darren Sudman  
Ralph and Deb Thibodeau  
Mary and Joel Turner  
Darla Varrenti  
Kimberly Waltman  
Michele Wenhold  
Ryan Zemke  
Karen and Jim Zilinski

“Parent Heart Watch was the reason I started KEVS Foundation. I could’ve gone in two different directions – grieve and hibernate for the rest of my life, or make sure I do everything possible in my child’s name so that it doesn’t happen to another family.

Parent Heart Watch provides the framework with great mentors so it is a launching pad.

In the midst of the sorrow of loss, it is community of giving people - it is really a gift.

— SUSAN CANNING, KEVS Foundation, Southampton, MA
Because of you...
lives have been saved.

We appreciate everything you have done for our mission in 2016.
“Parent Heart Watch sets the bar for sudden cardiac arrest prevention in youth. We get the support we need to make change. Together we go to great lengths to protect our children from heart issues and educate them about how to respond to a cardiac emergency. We yell from the mountain tops that our children need to be safe, screened and have easy access to AEDs. Parent Heart Watch is the leader, and we all follow the leader.”

— PAM FOSTER, Hawaii Heart Foundation