



**Parent Heart Watch®**

THE NATIONAL VOICE  
PROTECTING YOUTH FROM SUDDEN CARDIAC ARREST

800.717.5828 • [ParentHeartWatch.org](http://ParentHeartWatch.org)

*The faces depicted on the cover represent the children of Parent Heart Watch as of 2019, those lost in black and white and survivors in color. This represents a mere fraction of youth stricken by sudden cardiac arrest each year.*



**COLLABORATE.  
ADVOCATE.  
CHANGE.**

Parent Heart Watch  
Annual Report 2019



It has been both a challenging and rewarding year for Parent Heart Watch. On a national and local level, together we continue to elevate the groundswell of demand for better sudden cardiac arrest prevention protocol where youth live, learn and play. And yet, we continue to witness youth lost to what we know in our hearts and minds can be prevented.

This year, we came together to support our national movement, which in turn, has ensured continued progress to protect young hearts. Parent Heart Watch continued to raise awareness, place AEDs and implement cardiac emergency response plans in schools across the country through Get Charged Up! Our co-founded Call-Push-Shock campaign attracted significant attention,



including the opportunity to present and promote it at national and international conferences. We perpetuated hard-hitting social media campaigns that engaged a record number of families in the dialogue to improve SCA prevention. The Cardiac Safety Research Consortium pilot got the green light to commence, and we look forward to participating in an inaugural effort to ultimately establish a meaningful cardiac risk assessment standard for all youth.

As a national movement we take great pride in each other's accomplishments. And with one, unified voice, we will realize our vision to eliminate preventable deaths and disabilities from sudden cardiac arrest in youth by 2030.



*Karen Acompora*

Karen Acompora, Chair, Board of Directors

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## Staff

Martha Lopez-Anderson, Executive Director • Maureen Legg, Development & Communications Manager

Parent Heart Watch is the only national voice solely dedicated to protecting youth from sudden cardiac arrest (SCA) and preventable sudden cardiac death. Founded in 2005 by four mothers who lost their seemingly healthy child to an undetected heart condition, PHW has grown from a grassroots network into a national movement to protect young hearts.

Parents who have lost a child to SCA or whose child is an SCA survivor or is living with a heart condition are joined by medical professionals and other passionate advocates to advance life-saving initiatives that drive the national dialogue on prevention.

Studies show that 1 in 300 youth has an undetected heart condition that puts them at risk. The lack of national prevention standards much less education around what sudden cardiac arrest is marginalizes the reality that it is the number one killer of student athletes and leading cause of death on school campuses.



But the momentum of our mission to lead and empower others by educating and advocating for change has triggered research, registries and prevention initiatives to change the paradigm of youth lost. In fact, prior to our founding, young sudden cardiac arrest victims weren't even being counted. Reports now indicate progress, from an estimated 16,000 youth stricken in 2009, to 12,500 in 2013, to 9,500 in 2014 to around 7,000 currently.

Our pride resonates in this evidence of lives saved thanks in part to our passionate and unwavering commitment to protect young hearts where kids live, learn and play.

# Parent Heart Watch By The Numbers



**7,284 AEDs Placed to Date**

(818 in 2019\*)  
PHW members place AEDs wherever youth congregate, now protecting tens of thousands.

**34,904**

**Education Materials**

PHW provides resources to raise SCA awareness among millions of people.



**688,437**

**Screened to Date**

(105,296 in 2019\*)  
Member organizations in 29 states offering free or affordable screenings identified 2,000 with cardiac abnormalities



PHW supports passionate champions' efforts to launch community prevention initiatives.

**11 Presentations & Exhibitions**

PHW traveled the country speaking to thousands of advocates, educators, medical and allied health professionals.

**352,000**

**Video Views**  
Our video library continues to respond to the critical need to raise awareness of SCA prevention.

**478 Inquiries**

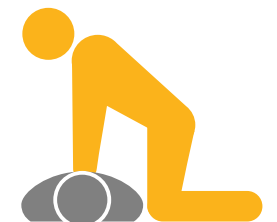
PHW personally responded to hundreds seeking direction, from families with a child stricken by SCA, to prevention advocates to media and legislators wanting resources.

**2 Million Social Media Reach**

580 posts each to Facebook and Twitter covering the latest news on losses, saves, research, resources and more caused heightened engagement.

**501,014 Trained to Date**

PHW members show how CPR + AED can save lives.



**Website Visitors**

Our website doubled its visitors seeking a comprehensive educational resource that looks at SCA from all sides.



**2,108 Prevention Promises**

Declaring we need better SCA prevention policies and practices, people across the country agreed to champion this national movement in their community.

\*Represents ~65% of member foundations reporting. Actual outcomes are higher.



# Our Programs

## Operation Prevention

Operation Prevention is a dynamic and transformative education program:



### 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.

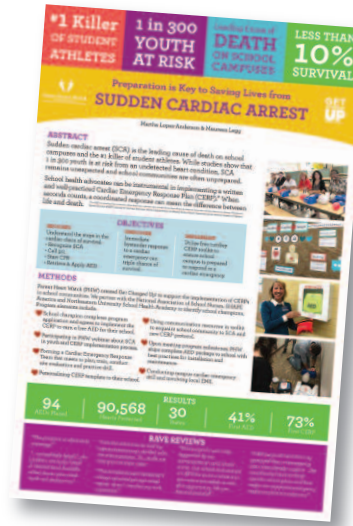


### WE EQUIP CAREGIVERS

with the knowledge and  
tools to protect the young  
hearts with which they  
are entrusted.

## Educational Advocacy

We educate stakeholders in school, sports and medical communities on the critical need for better sudden cardiac arrest prevention practices and protocol anywhere youth congregate. We forge meaningful partnerships with and make annual presentations to thousands of members of regional and national organizations across the country. As an information storehouse, we track youth lost to sudden cardiac arrest, which was the underpinning of our ability to catalyze the national Sudden Death in the Young Registry. We partner on research studies to affect policy change, and we co-author statements and resources to highlight the critical need to establish prevention protocol.



# Our Programs



## Heart to Heart

This dynamic three-day education platform kicks off Operation Prevention each January through a total immersion in the latest research and best practice protocols from industry experts on SCA prevention. Attendees include Parent Heart Watch members who advocate for SCA prevention in youth in their communities through professional work, education and outreach and service programs. To date champions have provided thousands of free or low-cost youth heart screenings, CPR/AED training and AEDs. Together these national champions fuel our movement to protect young hearts.



## Get Charged Up

As co-author with the American Heart Association and 12 national health and safety organizations of the Cardiac Emergency Response Plan for Schools policy statement, template and implementation resources, this program models the importance of automated external defibrillators (AEDs) and Cardiac Emergency Response Plans (CERPs) in schools. In collaboration with allied health professional associations, PHW mentors schools in CERP implementation, which in turn earns them a free AED and accessories. To date CERPs have been implemented in 94 schools in 30 states.



ParentHeartWatch.org



# Highlights of 2019

## Preparing Schools to Prevent Sudden Cardiac Death (SCD)

Sudden Cardiac Arrest (SCA) is the leading cause of death on school campuses and the #1 killer of student athletes

Parent Heart Watch was part of the American Heart Association national task force to create a cardiac emergency toolkit to help prevent SCD in school communities

CERPs include

- CPR/AED trained team
- Written response plan
- Accessible & maintained AED
- Cardiac emergency drill
- Communication with EMS & school community

Since 2017 Get Charged Up has provided **94 AEDs** to **30 STATES** who implemented Cardiac Emergency Response Plans (CERPs)

**79%** of schools hosted student athletes

The program has protected 90,607 hearts plus 1800s more given an estimated 20% of the population is on a school campus each day.

PHW collaborates with our member foundations and school nurses, health and physical educators to support CERPs in schools.

## Rave Reviews

*This entire experience has been wonderful and all help I have gotten has been great!*

*Everything was laid out and user friendly. We knew what each next step was.*

*I promoted the free AED as the prize for everyone's cooperation and assistance and things went very easily!*

*We had just developed a Crisis Team for building safety, so I asked their interest in developing a CERP with me... everyone said yes!*

*Local fire department happy to have this emergency response team at school and have combined them to be part of the stop the bleed program.*

*I did get push back from my principal that an emergency plan was already in place. She was shocked at how vague our supposed plan actually was.*

*Our school and staff were totally on board and ready to do whatever it took to better our school and the safety of our kids.*

## We Got Charged Up!

Working with Northeastern University School Health Academy and SHAPE America, Year 3 of our program equipped 27 schools in 17 states with new AEDs after they worked with PHW to implement a Cardiac Emergency Response Plan on their school campus. Earning 5-heart accolades from participants, the program inspired the majority to pursue ongoing activities, such as CPR/AED training, drills, speakers and lesson plans on prevention.

This program was made possible by



# Highlights of 2019



## Moving Pictures

Topping 350,000 views, our video library added *Who is Parent Heart Watch* to invite advocates to join our movement to eliminate SCA in youth.

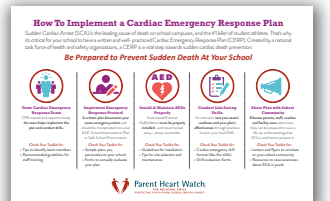


## Truth Hurts

Hard-hitting messages urging parent, education, sport and medical communities alike to acknowledge the lack of meaningful SCA prevention protocol engaged a record-breaking number of public opinion posts from across the country.

## Call • Push • Shock

Our national campaign in collaboration with SCA Foundation to champion a universal call to action is being perpetuated by 35 co-partners (and growing!) eager to respond to the Institute of Medicine's call to action to leave our silos and work together to engage bystanders in how to save a life. The research-driven campaign was invited to be featured at national and international conferences in the coming year.



## Spreading the Word

More than 34,000 free materials were requested from prevention champions around the country, enabling us to educate thousands about warning signs, risk factors, early detection heart screenings and the cardiac chain of survival to protect young hearts.



# Highlights of 2019

## Back to School

PHW is working with Northeastern University School Health Academy to develop a CNE for school health professionals on how to implement a cardiac emergency response plan at school to combat the leading cause of death on campus. The training module development will be informed by a needs assessment survey that captured responses from 500+ participants.

The survey revealed that:

- School nurses are predominantly responsible for managing cardiac preparedness
- More than half of schools don't have a cardiac emergency response plan beyond calling 911
- Their biggest challenge is not just funding an AED but ongoing maintenance costs
- One third of school staff and the majority of students and parents don't understand SCA can happen in youth
- One third of school staff and the majority of students and parents don't understand that an SCA victim's heart has stopped
- Two-thirds of staff and nearly all students and parents don't realize that gasping or movement does not mean an SCA victim is breathing
- One quarter of staff and three quarters of students and parents do not understand that immediate bystander intervention is critical to survival
- About half the population of school communities are not aware that CPR can triple the chance of survival, nor that anyone can use an AED—it will not hurt the victim



## SCA Advocacy

Presentations, training, staff development, keynotes, panel participation or testimony on SCA prevention was given across the country to thousands of key stakeholders.

- Brevard County Public Schools Board, Viera, FL
- Project ADAM National Meeting: National Partnership Initiatives, Ann Arbor, MI
- National School-Based Health Care Convention, Washington, DC
- "Raising an Athlete" by Vidant Medical, East Carolina Prevention Center, Greenville, NC
- Ocoee Middle School, Ocoee, FL
- 11th Annual Go for the Greens, Orlando, FL
- Resuscitation Science Symposium, Philadelphia, PA
- Cardiac Arrest Survival Summit, Seattle, WA

Additionally, PHW supported the Walters Family at multiple community events to raise awareness and provide skills training following the death of their son, Hezekiah, at school, during football practice.

# Highlights of 2019



## The Voice of SCA in Youth

Parent Heart Watch advocates for SCA prevention in youth in collaboration with numerous national organizations and working groups.

### American Academy of Pediatrics

- Section of Cardiology and Cardiac Surgery Advocacy and Public Policy
- Section of Cardiology and Cardiac Surgery Publications and Communications

### National Cardiac Arrest Collaborative

Following the recommendations of the Institute of Medicine to leave our silos and come together to create a universal message on bystander engagement in a cardiac emergency, PHW is a member of this collaborative.

### Sudden Cardiac Arrest Foundation

Ongoing collaboration to grow the Call-Push-Shock movement, including its presentations at national and international conferences.

### Cardiac Safety Research Consortium

The National Cardiac Screening Warehouse Pilot Study is fully funded and commencing with the support of PHW and several of its member screening programs to ultimately establish a national screening data warehouse.

### Sudden Death in the Young Case Registry

PHW continues to sit on the Advisory Committee of this effort to improve post-mortem diagnosis of SCA to obtain a more accurate count of youth lost.

### SHAPE America

PHW collaborated for a third year on a program to engage physical educators in championing cardiac preparedness on their school campus.

### Northeastern University School Health Academy

PHW is collaborating with these academic experts in school health to identify resources to help make more campuses heart safe.

# Special Thanks to our Donors

**\$50,000 & Above**

Dave & Susan Fiorelli

**\$15,000–\$49,999**

Louis J. Acompora Memorial Foundation

Cardiac Science Corporation

Firehouse Subs Public Safety Foundation

**\$2,500–\$14,999**

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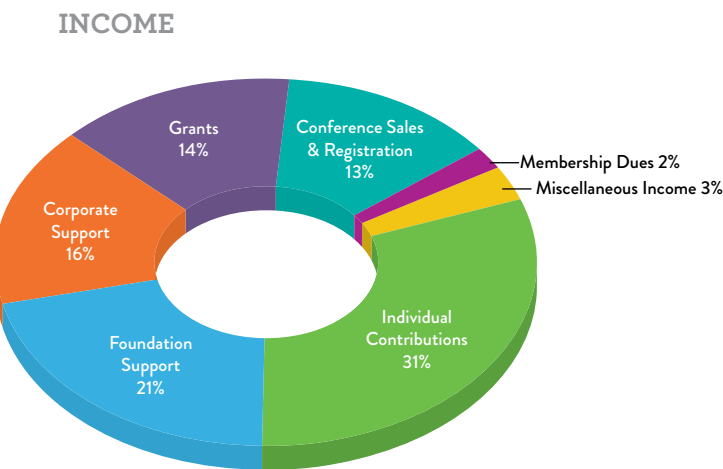
Amy Travioli

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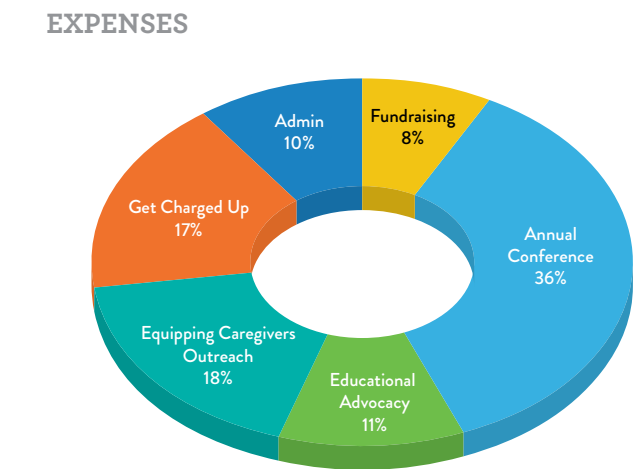
*Includes donation period of October 1, 2018–September 30, 2019*

Thank You to Our Donors

# 2019 Financial Report



PUBLIC SUPPORT	2019	2018
Individual Contributions	\$92,474	\$120,253
Foundation Support	\$63,905	\$52,455
Corporate Support	\$46,594	\$32,376
Donated Services	\$0	\$2,000
Gifts in Kind	\$0	\$17,398
Total Public Support	\$202,973	\$224,482
OTHER REVENUE	2019	2018
Grants	\$41,915	\$23,500
Conference Registration & Sales	\$37,459	\$30,089
Membership Dues	\$5,333	\$5,822
Miscellaneous Income	\$9,986	\$6,806
Total Other Revenue	\$94,693	\$66,215
Total Income	\$297,666	\$290,699



PROGRAM SERVICES	2019	2018
Annual Conference	\$97,672	\$89,741
Educational Advocacy	\$31,189	\$37,196
Equipping Caregivers–Outreach	\$47,927	\$43,990
Get Charged Up!	\$45,732	\$15,069
Total Program Services	\$222,520	\$185,997
SUPPORT SERVICES	2019	2018
Administration	\$27,924	\$15,340
Fundraising	\$21,909	\$39,576
Total Support Services	\$49,833	\$54,916
Total Expenses	\$272,353	\$240,913

76% of our expenses dedicated to programming

# Heroes for Young Hearts Awards

This outstanding group of sudden cardiac arrest prevention champions was honored at the 14th Annual National Heart to Heart in Houston for their dedication and commitment to the cause.



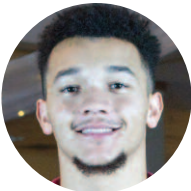
**Susan Fiorelli**  
Texas  
Founders’ Award



**Thomas DeBauche, MD**  
Cody Stephens Go Big or Go Home Memorial Foundation  
Medical Professional Advocacy Champion



**Amy Walker**  
Heart of a Husky, North Carolina  
Adult Advocacy Champion



**Xavier Hendrix**  
Who We Play For, Florida  
Youth Advocacy Champion



**Lexi Sima**  
Who We Play For, Florida  
Young Survivor Champion



**Women’s Auxiliary, Texas**  
Dana Holden, Sherri Juniel, Melody Stephens & Amy Travioli  
Local Hero Champions



**Scott Driscoll**  
Quinn Driscoll Foundation  
Hero In Memoriam

FY2019 financials include October 1, 2018–September 30, 2019