

# Changing the Standard of Care

Annual Report 2021



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



Resilience. It's a watch word for Parent Heart Watch members who practice that every day as we marshal our personal experience to protect other families from sudden cardiac arrest in youth.

The same resilience helped us navigate a global pandemic and continue to advance our mission.



Heart to Heart is the foundation of our national movement, so while others were pausing annual events, we created a successful virtual learning and networking environment to inspire our work.

We saw regional legislation on SCA prevention passed. We pivoted to adopt new protocol to safely offer free youth heart screening. We participated in the Cardiac Safety Research Consortium's national pilot study on ECG data collection. We contributed to the dialogue on evolving youth heart screening protocol. And we created a partnership to offer remote skills verification training for 100% CPR/AED certification from your home or office.

That's what it takes to change the standard of care.

Together We Will.

*Karen Acompora*

Karen Acompora, Chair, Board of Directors

Co-Founder, Louis J. Acompora Memorial Foundation



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# Changing the Standard of Care

Our vision to eliminate preventable deaths and disabilities from sudden cardiac arrest by 2030 is a tribute to the over 23,000 families whose child is lost to SCA each year. Many of those families are part of our national movement to protect young hearts. We are joined by thousands of allies and advocates who are passionately advancing initiatives to change the standard of care.

## **Creating a culture of prevention where youth live, learn and play.**

- ♥ Significantly increased awareness of SCA in youth
- ♥ Better cardiac risk assessment protocol at home and with medical providers
- ♥ Making cardiac screening a part of preventative care
- ♥ Empowering bystanders to Call-Push-Shock to save a life
- ♥ Placing AEDs in schools to prevent the leading cause of death on campuses
- ♥ Training youth sports communities to recognize and respond to the #1 killer of athletes
- ♥ Advocating for life-saving legislation and policies both regionally and nationally

*Founded in 2005 by four mothers looking to make sense of a tragedy no one warned them about, we have become the only national voice solely dedicated to the prevention of SCA in youth. Parent Heart Watch has come so very far. But, as long as young people continue to die, we will uphold our mission to lead and empower others by educating and advocating for change.*



# Parent Heart Watch By The Numbers



**9,228 AEDs  
Placed to Date**

(1,597 in 2021)

PHW members place AEDs wherever youth congregate, now protecting tens of thousands.



**2,246  
Prevention  
Promises**

Public declarations for better SCA prevention policies and practices.



**Website Visitors**

Serving thousands seeking our comprehensive educational SCA prevention resources.



**6 New  
Prevention Programs**

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



**564,000**

**Social Media Reach**

Hundreds of posts to Google, Facebook, Twitter and Instagram covering the latest news on losses, saves, research, resources and more supports our mission to educate.



**9,092  
Coach SCA  
Prevention  
Trainings**

In partnership with Coach Safely and the Eric Paredes Save A Life Foundation, this free training helps teams to stop leaving kids' hearts on the field.



**43 Call Push  
Shock Partners**

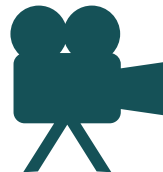
A national collaboration to affect bystander intervention in a cardiac emergency.

**23 SCA  
Bills**

PHW supported enacted and pending legislation on CPR, AEDs, cardiac emergency response plans and cardiac risk assessment.

**6 Presentations  
& Exhibitions**

PHW connected with thousands of advocates, educators, medical and allied health professionals.



**435,755 Education Materials  
& Video Views**

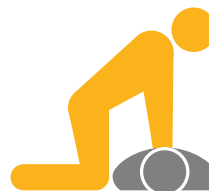
PHW provides free resources to raise SCA awareness among millions of people.



**800,912 Young Hearts  
Screened**

(51,771 in 2021)

PHW member screenings identify risk factors and conditions that may lead to SCA.



**608,953 CPR/AED  
Trained**

(26,944 in 2021) PHW members show how CPR + AED saves lives.

# Our Programs



## Heart to Heart

Our national platform for change is an annual springboard for community programs across 40 states. Without a national standard for SCA prevention for youth, this educational event shares innovative and effective working models that provide real-time solutions to fill this gap in health and safety protocol in youth communities. It has catalyzed the provision of hundreds of thousands of free or low-cost services and has informed new research, pilots and prevention policies.

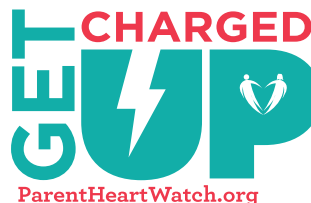
"At our first Heart to Heart, we met other parents who inspired us to share our son's story of survival as a means of educating others about how youth heart screenings and Cardiac Emergency Response Plans save lives."



## Advocacy

We educate change makers in school, sports and medical communities on the critical need for better SCA prevention anywhere youth congregate. We forge meaningful partnerships that inform thousands of professionals across the country. We track youth lost to SCA, which helped catalyze the Sudden Death in the Young Case Registry. We partner on research studies to affect policy change and co-author statements and resources to highlight the critical need to change the standard of care.

"It has been a privilege to work with Parent Heart Watch on educating families and health care providers about better investigation of young sudden deaths."



## Get Charged Up

As co-author with 12 national health and safety organizations of the Cardiac Emergency Response Plan (CERP) for Schools, we created this program to mentor school health professionals to implement a CERP on their campus, which earns them a free AED and accessories. We partner with the National Association of School Nurses, AED manufacturers, distributors and other vendors to help create heart safe campuses.

### CERPs include:

- Team trained in recognition of SCA, CPR & use of AED
- Written school CERP
- Accessible & maintained AED
- Emergency response drills
- Communication with EMS & school community



## Take the Prevention Promise

National call-to-action campaigns educate communities and equip hundreds of thousands with free SCA prevention resources for families, schools, teams, community centers, workplaces and medical practices. Through social media, printed and digital tools, articles, videos and more, we mobilize the next generation of lifesavers to recognize the incidence of SCA in youth and demand comprehensive cardiac risk assessment and cardiac preparedness to protect young hearts in youth communities.

97,335 Educational Materials  
338,420 Video Views

# Highlights of 2021



## Learn Life-Saving Skills From Home: Protect Young Hearts Across the Country

A key pillar of our Vision 2030 is to empower the public to respond to a cardiac emergency. CPR alone can triple an SCA victim's chance of survival and using an AED within the first minute of collapse can increase survival as high as 90%. That's why PHW partnered with the Health & Safety Institute (HSI) to offer HSI's Remote Skills Verification (RSV) training technology for First-Aid, CPR and AED. The program features:

- Full 2-year certification from home or work
- Interactive, remote, online learning
- Hands-on skills training
- Live instructors provide real-time feedback



Participants receive a discounted rate for the course, with that savings donated back to support our national movement to raise the standard of care.



## Keeping Kids' Hearts in the Game

Parent Heart Watch partnered with the Eric Paredes Save A Life Foundation and Coach Safely, a leader in youth sports injury prevention and education, to create sudden cardiac arrest prevention training for youth sports communities. The training is available to teams to support compliance with state sudden cardiac arrest prevention and sports safety laws, as well as anyone committed to comprehensive health and safety standards to protect young athletes.

A pre-and post-quiz measures improvement in SCA awareness, warning signs, risk factors and what to do in a cardiac emergency.

**Average quiz scores increased from 69% to 91% after taking this training!**



# Highlights of 2021



## Getting Schools Charged Up

In 2021, we doubled the size of our program to place 53 AEDs and implement cardiac emergency response plans (CERP) in schools across the country. To date, our efforts are protecting the hearts of nearly 150,000 students and staff, plus thousands more given an estimated 20% of the population is on a school campus on any given day.

### Since 2017

- 153 AEDs to K-12 schools • 35 States
- 32% Schools' 1st AED • 59% Schools' 1st CERP
- 20% SCA on Campus



## Shaping the Future of ECG Testing

Parent Heart Watch members have provided tens of thousands of data points from their free youth heart screenings to the *Prevention of Sudden Cardiac Death in the Young: National Cardiac Screening Warehouse Pilot Study*.

Analysis of the data will allow

understanding and improvement of

screening efficiency and impact, potentially allow revision of criteria for abnormal ECGs in children, and could ultimately inform making ECG testing part of preventative care.



**CARDIAC SAFETY**  
RESEARCH CONSORTIUM

*"The collaboration between members of PHW, Duke, the CSRC, and the FDA has been essential to the success of this pilot study. This project, which could change the face of screening across the country, would not be in place without the dedication and commitment of PHW members to the cause."*—Salim F. Idriss, M.D., PhD, Duke University



# Highlights of 2021



## **The Voice of SCA In Youth**

Parent Heart Watch advocates for SCA prevention in youth in collaboration with numerous national organizations and working groups through presentations, training, staff development, keynotes, publications, panel participation or testimony on SCA prevention given across the country to thousands of key stakeholders.

**National Association of School Nurses—Virtual**

**Safe Kids Worldwide Childhood Injury Prevention Convention—Virtual**

**National Association of Pediatric Nurse Practitioners**

**American Academy of Pediatrics National Conference & Exhibition—Virtual**

**Cardiac Arrest Survival Summit**

**Columbia University’s “Complicated Grief”**

Research Talks Webinar—Understanding bereavement and caregiving after cardiac arrest



## **New Policy To Heart Screen All Youth**

Parent Heart Watch is part of the ongoing dialogue to evolve recommendations from the American Academy of Pediatrics (AAP) for combating Sudden Death in the Young. Developed by the AAP Section on Cardiology and Cardiac Surgery and the Pediatric and Congenital Electrophysiology Society (PACES) Task Force on Prevention of Sudden Death in the Young, a new 2021 policy offers guidance to help primary care providers identify children with at-risk heart conditions. Providers now have a strategy for screening, evaluating and managing cardiac risk assessment during well-child checks and preparticipation physical evaluations or at least every three (3) years and especially upon entry to middle/junior/high school, regardless of the level of physical activity, which was the previous benchmark, and to use ECG testing to address concerns. While not addressing the asymptomatic child with regular ECG testing, the new guidance is a step forward in preventative care.

# Special Thanks to our Donors

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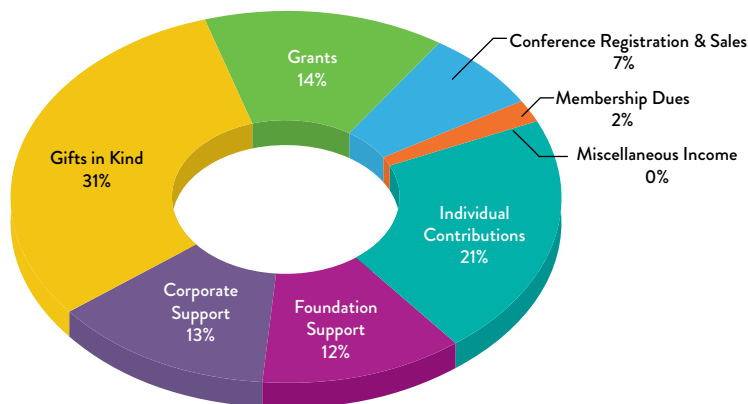
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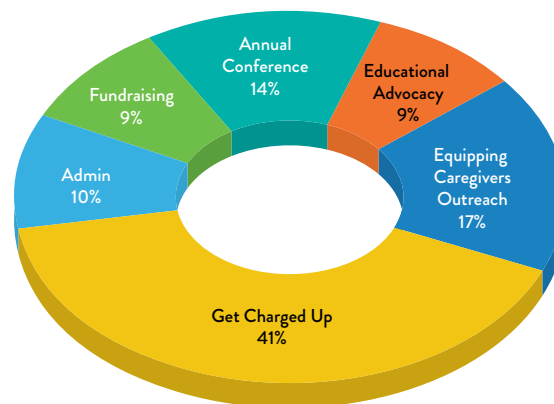


# 2021 Financial Report

## INCOME



## EXPENSES



### PUBLIC SUPPORT

	2021	2020
Individual Contributions	66,883	69,745
Foundation Support	38,000	34,150
Corporate Support	40,344	32,500
Gifts in Kind	96,682	0
<b>Total Public Support</b>	<b>241,909</b>	<b>136,395</b>

### OTHER REVENUE

	2021	2020
Grants	43,470	10,000
Conference Registration & Sales	20,090	52,938
Membership Dues	6,126	4,920
Miscellaneous Income	855	9,741
<b>Total Other Revenue</b>	<b>70,540</b>	<b>77,599</b>
<b>Total Income</b>	<b>312,450</b>	<b>213,994</b>

### PROGRAM SERVICES

	2021	2020
Annual Conference	38,800	94,452
Educational Advocacy	26,521	25,102
Equipping Caregivers-Outreach	48,324	45,302
Get Charged Up!	114,983	11,888
<b>Total Program Services</b>	<b>228,629</b>	<b>176,745</b>

### SUPPORT SERVICES

	2021	2020
Administration	28,662	30,000
Fundraising	23,733	21,509
<b>Total Support Services</b>	<b>52,396</b>	<b>51,509</b>
<b>Total Expenses</b>	<b>281,025</b>	<b>228,254</b>

81% of our expenses dedicated to programming

FY2021 financials include October 1, 2020–September 30, 2021

# Heroes for Young Hearts Awards

This outstanding group of sudden cardiac arrest prevention champions was honored at the 16th Annual National Virtual Heart to Heart for their dedication and commitment.



Adult Advocacy Champion  
**Austin McAnena**  
California



Founders' Award  
**Salim Idriss,**  
**M.D., PhD., FACC, FHRS**  
Pennsylvania



Medical Professional Advocacy  
Champion  
**Shawn Sima, PA**  
Florida



Young Survivor Champion  
**Julieta Valdes**  
Texas



Youth Advocacy Champion  
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