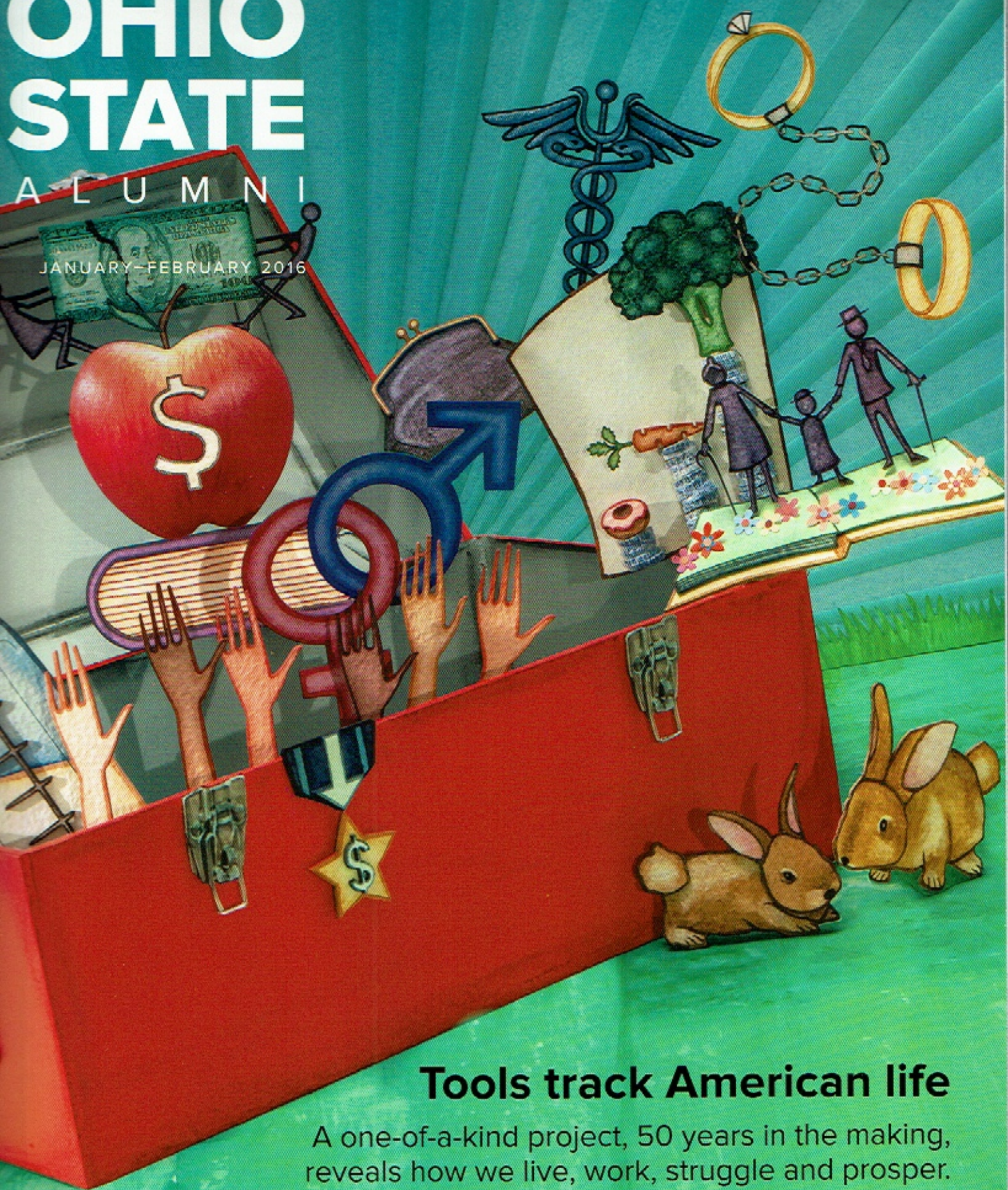


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Heart to heart

Inspired by an infant and fueled by his parents' love, Simon's Fund is saving lives around the country.

By Kim Bonvissuto

Simon Sudman was 3 months old when his heart just stopped. His mother had put her seemingly healthy baby boy down for a nap one day in 2005 and he never woke up.

At that moment, Darren and Phyllis Sudman were thrust into an unfamiliar world, one revolving around sudden cardiac arrest, a malfunction within the heart's electrical system that causes the heart to stop beating. They remain a part of that world, although today it is by choice.

The American Heart Association estimates 300,000 sudden cardiac arrest (SCA) incidents occur in the United States each year, about 5,900 involving children. According to the

American Academy of Pediatrics, SCA claims the lives of about 2,000 children each year.

As the Sudmans soon learned, few people know much about SCA or even think about heart trouble in kids. They also discovered there is no medical standard for checking children's hearts.

"The heart beats 2,000 times a day. Not to deal with it until you are 45 or 50 is idiotic," said Darren Sudman '92. "[In many states] you have to get your car inspected every year. Why can't we be checking our kids' hearts?"

The Sudmans were told Simon's death resulted from Sudden Infant Death Syndrome.



Yu Kwan Lee/Cleveland Clinic

Darren and Phyllis Sudman

"We learned that doesn't mean anything," said Phyllis Satinsky Sudman '93, tearing up as she recounted the tragedy 10 years ago that changed her family forever. "Babies don't die without a reason."

The parents were encouraged to have their own hearts checked, and Phyllis' screening revealed she has long QT syndrome, a genetic heart arrhythmia she unknowingly passed to her son.

In their grief, the Sudmans were blessed with an incredible outpouring of support.

"We raised \$21,000 without knowing what we were going to do," Phyllis said. "Within three months we had Simon's Fund set up as a 501(c)3. We didn't want another family to go through what we went through."

Simon's Fund is dedicated to raising awareness about the conditions that lead to SCA and death in children and young athletes.

Over the past decade, the nonprofit has raised close to \$2.5 million, mostly through an annual gala, golf outing and 5K run. The organization hosts heart screenings, advocates for laws to identify SCA in children, and supports research and medical fellowships. Its work has

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— Phyllis Satinsky Sudman

led to heart screenings for 12,000 children — about 1 percent of whom have been found to have previously undiagnosed heart conditions.

"Think about it," Darren said. "You get your eyes and ears checked, but not your heart. I don't understand why that's not the standard."

The Sudmans — through detection, innovation, education and legislation — are working to change that.

Detecting the problem

Darren and Phyllis began their work close to home by providing free heart screenings for children in the Greater Philadelphia area. Local

medical centers, physicians, schools and corporations got on board early.

At each session, children and parents move through a series of stations. Family medical histories and vital signs are recorded. Electrocardiograms (ECG) are conducted. And education sessions cover CPR and automatic external defibrillators. If a screening suggests an irregularity or high-risk factor, an echocardiogram is conducted on-site.

Melissa Fair was 10 years old when her mother brought her to the very first Simon's Fund screening. A cheerleader, she was an active child and, by all accounts, perfectly healthy. The screening proved otherwise.

An echocardiogram detected a congenital birth defect: an out-of-place vein and a hole in Melissa's heart. She underwent open-heart surgery on Jan. 24, 2008, three years to the day after Simon died. Today, she is a healthy 18-year-old Penn State freshman.

"She could have dropped dead," said Lori Fair, Melissa's mother. "They saved her life. If it hadn't been detected, five to 10 years down the road the scarring would have been so bad it would have been difficult to repair."



Yu Kwan Lee/Cleveland Clinic

Darren Sudman teaches kids about their hearts during a screening co-sponsored by Cleveland Clinic last year.

The Fairs' gratitude to Simon's Fund led to action. After she recovered, Melissa sold bracelets as her bat mitzvah project to raise money for the organization. Her father, Kenny, joined the Simon's Fund board of directors.

"We didn't even know the Sudmans. We heard about what happened to them and thought it would be crazy not to go to the screening," Lori Fair said. "Now they are like family. They saved my kid's life. It's incredible."

Such stories keep Phyllis going. She moves from family to family at the heart screenings to learn more about those Simon's Fund serves.

"That 3-month-old boy has had an impact on so many people's lives that most people don't have in a lifetime," Phyllis said of Simon. "Every time we touch a family's life, it's tremendous."

Branching out

While Simon's Fund operates mostly in the Greater Philadelphia area, its reach is growing.

The nonprofit recently hosted a free heart screening in the Cleveland area with the help of Dr. Peter Aziz, a pediatric electrophysiologist and director of Cleveland Clinic's Inherited Arrhythmia Clinic. Aziz

studies long QT syndrome and shares the Sudmans' goal of preventing SCA in children.

Scott Bottcher of Chagrin Falls brought his son, Cooper, 9, to the Cleveland screening. A soccer player for the past four years, Cooper already underwent a physical to play sports. But Bottcher said the heart screening his son got that day was especially important to his family.

"His mother had a heart attack at 35," Bottcher said. "This screening provided peace of mind."

Innovating for data

Simon's Fund is allied with ScreenAcrossAmerica.org, a nationwide consortium that provides heart screenings for students. But Darren said it's difficult to coordinate all of that information.

"Everything is paper-based," he said. "Volunteers are exhausted. Records end up in file boxes in the basement."

Looking for a way to easily sort and share data collected at heart screenings, the Sudmans developed Heart Bytes, a first-of-its-kind national youth cardiac registry of seemingly healthy children. The registry so far contains 4,000 digital records that include ECG images of and other

medical information entered via tablet computers at heart screenings.

Darren hopes this "free public library for researchers" helps the medical community better understand SCA in youth. He wants to collect more than 10,000 records to help researchers determine just how rare it is to find heart problems in children.

"Today, there is very little data about kids' hearts and virtually nothing on seemingly healthy kids," he said. "We can't figure out how many kids have undetected heart conditions without data. We can't figure out how many kids are hypertensive without data. We can't prove that adding an ECG to a physical helps detect heart conditions without data."

One researcher who hopes to benefit from the future database is Dr. Peter Mohler, director of Ohio State's Dorothy M. Davis Heart and Lung Research Institute. He is working with physicians, nurses, pharmacists and genetic counselors at the university's Richard M. Ross Heart Hospital to define new genetic and molecular diagnostics for cardiac arrhythmia and heart disease in children and young adults.

"Their mission is truly inspiring," he said of the Sudmans. "It motivates

us as scientists to work even harder to find solutions to these incredibly important and unsolved questions. The more data we have available, the easier it will be to understand how to identify and treat these complex diseases."

Despite great effort, the medical field still lacks robust tools to reliably identify cardiovascular disease in children, Mohler said. His team has linked numerous genetic markers to cardiac rhythm disturbances, work aimed at determining how many people are predisposed to SCA and identifying its causes.

When he discusses these efforts, Mohler refers to a "community" — people like the Sudmans and the family and friends of Connor Senn, who have turned a devastating personal loss into progress that helps others.

Senn was an 18-year-old freshman on Ohio State's men's soccer team when he collapsed during a match in 2001. He died that night. His congenital heart defect had never been detected.

Today, an annual soccer match in his honor raises funds for cardiac research at Ohio State and bolsters the Connor Senn Memorial Scholarship, which provides support for two undergraduates annually.

"Connor and Simon truly show the impact of cardiovascular disease on a community," Mohler said.

Sharing knowledge

Educating parents, children, teachers, coaches and medical professionals about SCA is important to the Simon's Fund mission.

For the past four years, the organization has hosted heart screenings at the site of the NCAA Division

Taking it to the Next Level

The Sudmans have had a hand in educating young athletes about the warning signs of sudden cardiac arrest from another Buckeye, Malcolm Jenkins '09, a safety with the Philadelphia Eagles.

The Malcolm Jenkins Foundation, established in 2010 to help kids in underserved communities, conducts an annual youth football camp called Next Level. The camp teaches skills to help youth succeed on and off the field. Last summer, Simon's Fund educated the kids about SCA.

"Although we were talking to adults about it, we had not addressed heart health with kids, in terms of what they need to know about it and how to recognize if they have symptoms,"

I Final Four. It's also partnering with the National Federation of State High School Associations to share a video on SCA with 1.5 million coaches. And this past summer, Simon's Fund partnered with Philadelphia Eagles safety Malcolm Jenkins '09 to inform young athletes about SCA.

Moving forward

After Simon's Fund ushered in the Sudden Cardiac Arrest Prevention Act in Pennsylvania in 2012, the Sudmans set their sights on the remaining 49 states. To date, similar laws are in effect in 10 other states, and legislation has been introduced in Ohio.

The laws require that information be provided to parents of student-athletes, ensure coaches complete training and mandate the removal of student-athletes who show warning signs of SCA.



Malcolm Jenkins' summer camp partnered with Simon's Fund last year.

said Jenkins' mother, Gwendolyn Jenkins, who leads the foundation.

A presentation showing the impact of exercise on the heart captivated the young audience.

Although nothing formal is in place, Simon's Fund and Next Level are looking at future opportunities to work together.

The Sudmans' efforts have captured national media attention and some well-deserved commendations. In 2014, Phyllis was named a L'Oréal Woman of Worth National Honoree for her work with Simon's Fund, which got a boost from the resulting \$35,000 monetary reward. The national organization of her college sorority, Sigma Delta Tau, named her alumna of the year that year, too.

The Sudmans said their family — including Sally, 13, and Jaden, 9, whom the Sudmans adopted from Guatemala the year after Simon's death — will forever be associated with Simon's legacy.

"His death transformed our family," Darren said. "I can't tell you how, because that normal died with him." ★

LEARN MORE

- Visit simonsfund.org to learn more about the Sudmans' work.
- For information on the Dorothy M. Davis Heart and Lung Research Institute at Ohio State, visit heartlung.osu.edu.
- Matthew Ritchey '07 MPH leads national cardiovascular health projects at the Centers for Disease Control and Prevention. Read about his work at go.osu.edu/ritchey.