



SURVIVOR NATION

THE NATION'S FIRST COMMUNITY OF SCA SURVIVORS

>> BY MARY NEWMAN

The National Survivor Network (aka, the Network), a program of the Sudden Cardiac Arrest (SCA) Foundation, has members in nearly every U.S. state and territory. The Network is a place where survivors of SCA can share their experiences and insights, provide mutual support, and find opportunities to pay it forward by raising awareness to help save other lives. The Network has its roots in several initiatives, some from long ago.

HOW IT STARTED

It was 1982. The Conference on Citizen CPR was held in Kansas City, Mo., that year. I was

working for Jim Page, executive director of the Advanced Coronary Treatment Foundation and founder of *JEMS*, so I was part of the conference planning committee. I remember we came up with the idea of identifying survivors who could share their testimonials and bring home the message to the audience—comprising mostly CPR instructors—that bystander CPR does save lives and their work truly matters.

The funny thing is, it was tough to find any survivors at all. This was a time when defibrillators were manual devices used mostly by physicians, paramedics and nurses. It was long before the advent of bystander

use of AEDs. As critical as CPR was even then, it simply couldn't deliver the same one-two lifesaving punch as the combination of immediate CPR and defibrillation.¹

A few days before the conference, we found ourselves lacking survivors to tell their tales. Just as we were about to abandon the concept, we identified three real-life saves involving area residents who were willing to share their experiences. Back then, so few people survived an SCA that they may have been the only ones out there.

The three Kansas City speakers were Gayle Koffman, Ron Babb and Robert Morantz, MD.

Gayle, then 10 years old, had saved her father by giving him abdominal thrusts when he was choking. She had seen a CPR demonstration in her fourth-grade class. "I was afraid that if I didn't do something fast, I would lose my Dad forever," she said, her father at her side.

Ron, an EMT instructor and father of three teenagers, also spoke. He had suffered a heart attack that led to cardiac arrest. "Ironically enough, CPR was given to me by some of the students I had recently certified," he said.

The third speaker was Robert Morantz, MD. He had been out jogging on a high school track when he nearly stumbled on an apparent victim of cardiac arrest. He gave the middle-aged man CPR while another jogger ran for help. The victim made a full recovery, and Dr. Morantz decided to spread the word on the importance of CPR training.

The "survivor" presentations turned out to be a highlight of the conference. Stories of survival energized the audience and helped renew their passion for the cause.

LOCATING SURVIVORS

Fast-forward 16 years. In *Challenging Sudden Death: A Community Guide to Help Save Lives*, a book I wrote with James Christenson, MD, we decided to feature a survivor story at the end of each chapter. Even then, successful cases were hard to find. But ones we did uncover invariably involved the prompt use of defibrillators.

One of the most memorable cases was that of Mark Vollmar. A police officer from Muncie, Ind., Mark was 41 when he suffered cardiac arrest while off duty in 1998. He had been driving into town with his two young sons when he suddenly slumped over. The nine-year-old son turned off the ignition, and the car coasted safely to a stop.

Two bystanders started CPR. Then, fellow police officer Daniel Hahn responded with his newly acquired AED, which he used for the first time. Until then, Hahn had actively opposed the idea that police officers should get involved with medical procedures. His attitude changed forever when he helped save the life of his friend and colleague.

THE SUMMIT

In 1999, I was working at the University of Pittsburgh Department of Emergency Medicine National Center for Early Defibrillation (NCED) program.

Increasingly, we began hearing amazing stories of survival. We recognized that if we could bring survivors together, they would benefit from meeting one another. Through the power of survivors, NCED could help raise awareness. Consequently, we hosted the first national meeting of SCA survivors, the Conference of Champions and Survivor Summit, in October 2003. We recruited 42 SCA survivors from more than 20 states, ranging in age from 12–76. Our target number of attendees was 42, because this was the number of people who suffered SCA every hour in the U.S.²

For survivors, this was an opportunity to find closure and a sense of community—to recognize they're not alone, but rather, part of a small but growing community. For each of the 250 EMS personnel who attended, the conference validated their life's work.

Kansas City, Mo., survivor Charlie Miller captured the spirit of the day when he said, "Although [our cases] may have been caused by many different things, we all survived because of early CPR and defibrillation. We all benefited directly from the champions of these procedures. You're truly making a difference that will mean literally thousands more survivors in our lifetime."

When the NCED met again in 2004, more than 60 survivors from across the nation attended. They shared their stories of survival and the ways they were giving back to help improve the chances of survival for future victims.

THE NETWORK

When NCED disbanded in 2005, the SCA Foundation was founded. The mission of this independent, non-profit organization was to continue to raise awareness of and save lives threatened by SCA.

The Foundation was launched in January 2006. Shortly thereafter, we launched the Network. This online community now includes survivors and their families who share experiences and help one another in the healing process. They also participate in research, awareness and advocacy initiatives designed to help save more lives.

Network Director Jeremy Whitehead says he was a stranger to SCA until his wife became a survivor and discovered she wasn't alone. Whitehead was attracted to the foundation because the organization

cared deeply about the survivors.

"The Network is a community of like-minded people that will soon become an army fighting to raise awareness about sudden cardiac arrest," he said.

With about 15,000 new survivors annually, the Network is now a microcosm that reflects a larger community. The Network database (n=300), represents a self-selected sample of web-savvy individuals, but nevertheless reveals some interesting characteristics of SCA survivors.

Most members are males between 31 and 60 years old, although 11% are 20 years or younger. About a third report they had no previously known heart condition. Twelve percent received therapeutic hypothermia. One third have implantable cardioverter defibrillators (ICDs). Most report they have returned to their pre-arrest mental and physical status. It's common, though, for survivors to suffer short-term memory loss, especially in the days immediately before and after the event. Some experience depression and survivor guilt.

In January, the Arizona Department of Health Services Bureau of EMS and Trauma Systems became the Network's first virtual affiliate. We envision the Network will continue to grow in the next few years, providing insights about survival and a voice for the thousands of SCA victims who don't survive. And we foresee a day when survival from sudden unexpected cardiac arrest is the rule, not the exception. **JEMS**



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This article reflects my experience with sudden cardiac arrest survivors, many of whom I'm honored to know personally.

REFERENCES

1. Newman M. CPR: It Keeps on Working. *JEMS*. 1982;7:55.
2. Newman M. Birth of a Tribe: The NCED SCA Survivor Network. *JEMS*. 2005;30:26–33.

FOR MORE ON THE NETWORK VISIT
www.sca-aware.org