

THE 6TH LINK OF SURVIVAL

Supporting Survivors and Bystanders
Following Sudden Cardiac Arrest

A SPECIAL SUPPLEMENT
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When a heart stops beating, emergency medical crews spring into action with one goal—get it beating again.

But even if all goes according to plan, and spontaneous circulation is restored, is the job of the medical community finished? Conventional healthcare has historically said yes—but groundbreaking research is beginning to shed light on the long and arduous journey that survivors of sudden cardiac arrest still must face.

“Sudden cardiac arrests are very different from other medical events,” says Sachin Agarwal, MD, founder and director of the NeuroCardiac Comprehensive Care Clinic at Columbia University. “The heart gives out, but the brain gives out too.” Even with a full restoration of cardiac function, a feeling of impending doom, depression, survivor’s

guilt and other distressing emotions can impede recovery and plague survivors for the rest of their lives.

The goal of Agarwal’s research is to promptly identify and address any neuro-cognitive and neurological complications and psychosocial problems among survivors, to minimize disability in both the short and long term, and to help reintegrate survivors into the community.

Agarwal’s work, as well as new attention to the difficulty that bystander rescuers experience—whether the outcome was a good one or a bad one—has led to a new “6th link” in the cardiac arrest chain of survival—improving survivorship outcomes. This e-book describes new research, community resources and survivor stories surrounding this critical chapter of recovery from sudden cardiac arrest.

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SUDDEN CARDIAC ARREST FOUNDATION

Making a difference in public health

By James Careless

Sudden cardiac arrest (SCA) is the Number One killer of Americans every year, with more than 325,000 dying of SCAs every year. The Sudden Cardiac Arrest Foundation (SCAF, a national community benefit 501(c)(3) organization) was launched in 2006 to lower this mortality rate.

“Our mission is to raise awareness about sudden cardiac arrest (SCA) and help save lives,” said SCAF cofounder Mary M. Newman, the foundation’s President and CEO. “We are working to improve the chances of survival from SCA through education, community support, and research.

In the area of education, the SCAF aims to triple survival rates by arming the public with first aid information that will help them save lives. To make this happen, “we are working on educational initiatives that increase bystander action during SCAs,” said Newman. This includes CPR training, AED placement/emergency response plans, and public awareness campaigns.

Providing community support and resources is another part of the SCAF’s survival enhancement approach. “We support thousands of families impacted by SCA,” Newman said. “We provide community resources that are vital to survival, including AED donations to churches, schools, and other community locations.”

This support also includes the SCA Network (<https://www.sca-aware.org>), a free online community open to SCA survivors, loved ones, and SCA survival advocates including EMS responders. “Sometimes survivors and loved ones just need to connect with someone who has walked in their shoes,” said Newman—“someone who understands, someone who has been able to move on and find a new purpose in life.”

In the area of research, SCAF knows the importance of “CPR in progress” when EMS arrives on scene. In collaboration with

StrataVerve, a strategic consumer research practice, SCAF has defined gaps in public awareness and understanding of SCA, CPR and AEDs. Importantly, research revealed key messages that motivate bystander action and tested a lay-friendly definition of SCA to educate the public and power Call-Push-Shock, a national movement co-sponsored by SCAF. (See <https://www.sca-aware.org/2017-study>.)

“We also collaborate with universities and hospitals to study the impact of SCA on the quality of life for survivors and their loved ones, plus ways to improve survivorship,” said Newman. The SCAF’s most recent research partners include Beaumont Health System, University of Colorado, University of Michigan/NIH Siren, and NYU Langone Health. (Some studies are ongoing. To learn more, go to www.sca-aware.org/sca-news/learning-from-cardiac-arrest-survivors-and-their-loved-ones.)

As SCAF celebrates its 15th anniversary, Mary Newman sees signs of progress in the fight to help more people survive SCAs. “It is absolutely wonderful that so many more victims of sudden cardiac arrest are surviving, thanks to increased awareness, dispatch-assisted CPR, immediate bystander action, and improved interventions by EMS and hospitals,” she said. “At the same time, we are facing new challenges, such as understanding how best to support survivors and loved ones in their journey going forward.”

Throughout these years, the SCAF has served as an information gateway for sudden cardiac arrest. “We are reaching tens of thousands of individuals through our website and social media outreach each month,” said Newman. “Going forward, we plan to continue serving in this capacity, and at the same time increase our efforts to support survivors and loved ones.”



It is absolutely wonderful that so many more victims of sudden cardiac arrest are surviving. At the same time, we are facing new challenges.

—Mary Newman, Sudden Cardiac Arrest Foundation

She added that the foundation appreciates the pivotal role played by EMS in improving SCA survival rates. “EMS providers are essential to saving lives from SCA,” Newman said. “This is why we report regularly on saves by EMS through our social media channels.”

“So many lives have been saved by EMS providers by those who are on duty, and also those who are off-duty who happened to be in the right place at the right time,” she concluded. “This is why we cannot say enough to recognize the work of EMS providers in the fight to save lives from SCA.”

AFTER THE EVENT: SUPPORTING SURVIVORS AND BYSTANDERS

By James Careless

According to the American Heart Association, there are about 350,000 out-of-hospital cardiac arrests (OHCAs) in the U.S. each year, and nearly 90% of them are fatal. This is why the fortunate few who do survive such are lauded as medical miracles.

Unfortunately, surviving an OHCA doesn't mean that the patient's life goes back to what it was before the attack. Many suffer serious aftereffects that impair their physical, mental, and financial well-being, as well as that of their families. Meanwhile, many of the bystanders who save these patients' lives through the speedy administration of CPR suffer trauma of their own, particularly because most OHCA resuscitation efforts are unsuccessful.

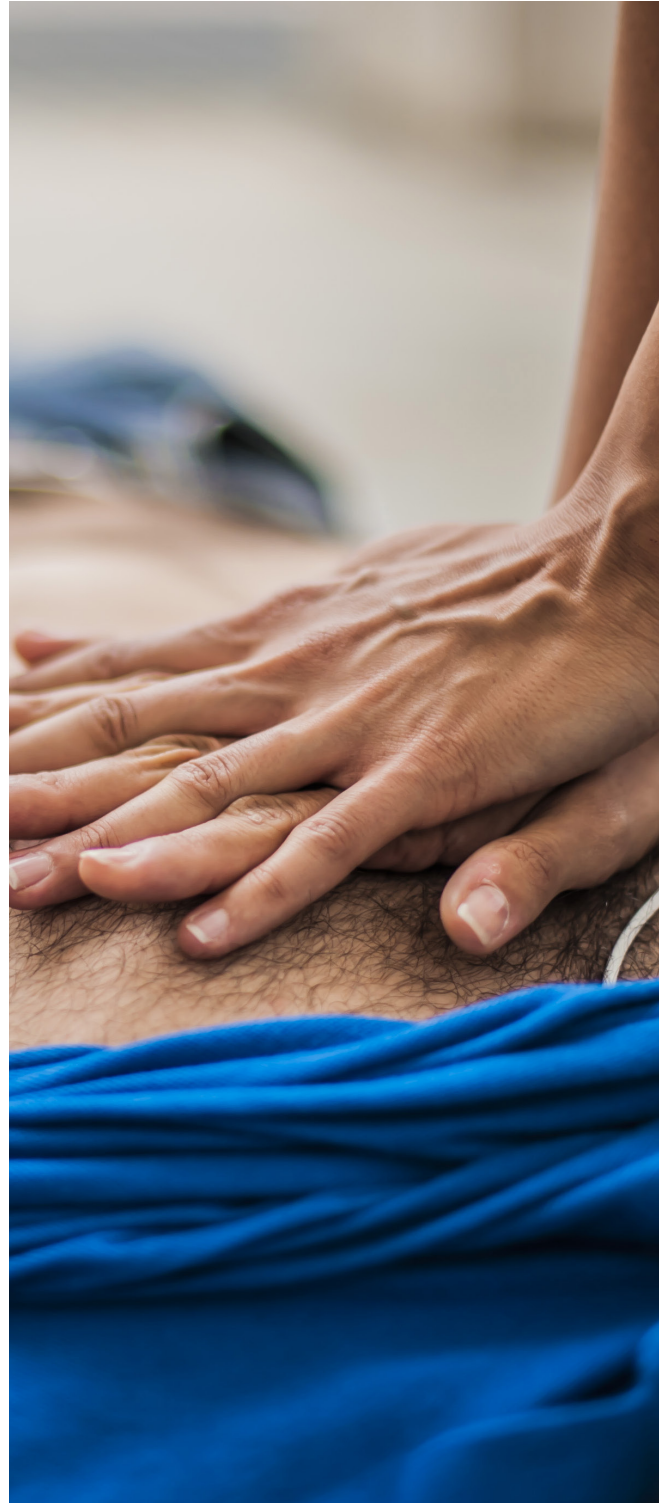
Supporting both OHCA survivors and bystanders is the mission of Katie Dainty, PhD, research chair in patient-centred outcomes at North York General Hospital. This is not an area she was focused on when she achieved her PhD from the University of Toronto in 2010. "But I found as I talked to OHCA survivors, their families, and the bystanders who helped save these patients' lives using CPR that there were various kinds of trauma that many of them had gone through. These are the kinds of issues that I and my colleagues are now trying to address through more patient-oriented research."

Surviving Isn't Enough

Perhaps because so few people currently survive OHCA, research into this topic has focused on improving the survival rate through public CPR education, widespread availability of automated external defibrillators in public areas, and better procedures and tools for EMS crews responding to such emergencies. "What researchers haven't done as much of is to consider what happens to OHCA survivors once they leave the hospital," said Dainty. "There are lots of life changes for many of them to cope with, and very little support."

The range of life changes faced by OHCA survivors is vast. For instance, some can't return to work. Those that can may not be able to do as much on the job as they could before. And others may experience changes to their physical, mental and emotional states that negatively affect their own view on the world and their relationships with others. (We live in a society that denies death as much as possible Dainty asserts. Many people who survive near-death experiences such as OHCA don't have the emotional tools to assimilate these terrifying realities.)

"OHCA can completely change a person," said Dainty. "Although followups with their cardiologist can address some of their physical issues, the medical profession hasn't spent a lot of time thinking about the psycho-social aftereffects of OHCA. That's the kind of qualitative research that we've been doing in my lab (and with colleagues worldwide) over the last few years, understanding what OHCA survival means to survivors and their family members, and how we





We really need to develop ways that we can measure outcomes that matter to OHCA survivors and their families, like quality of life and social functioning.

—Katie Dainty, PhD



can incorporate this knowledge into more effectively measuring OHCA outcomes. We really need to develop ways that we can measure outcomes that matter to OHCA survivors and their families, like quality of life and social functioning.”

The Plight of Bystanders

Bystanders are what has been described as the forgotten victims of OHCA incidents. Whether they are family members, friends or literally bystanding strangers who step into help during an OHCA, very little attention has been paid to the impact of these events on bystanders.

Quite often the after-event impact is significant, especially if the OHCA patient did not survive. “A lot of bystanders were glad that they responded to an OHCA event, but many suffer symptoms afterwards akin to PTSD,” said Dainty. “For instance, some have trouble sleeping, always wondering if they did helped or made it worse. Unfortunately in North America bystanders don’t receive feedback on whether the victim survived or whether what they did helped. Others simply feel isolated and alone, because

they don’t know any other bystanders with similar experiences that they could share their feelings with, to make sense of them.”

Dainty’s keen awareness of the “forgotten bystander” motivated her to found the Bystander Support Network (www.bystandernetwork.org/) in 2017. The BSN is a source of knowledge and support for OHCA bystanders, and includes an online network where they can chat with others who have undergone similar traumatic experiences, whether they intervened directly in an OHCA event or just witnessed one occur. “My goal is to help those everyday heroes who step in to save a life,” she said.

Takeaways for EMS

In the views of many, OHCA aftercare is not an EMS concern. That said, being aware of what OHCA survivors go through after leaving the hospital is useful knowledge for EMTs and paramedics, because these outcomes are related to their initial efforts. It’s all part of the “big picture” of saving lives.

However, helping bystanders with the experience is something that EMS crews can do, should the occasion arise in the

course of an OHCA call. Something as simple as telling them that what they did was amazing and helped the victim no matter what, mentioning resources like the Bystander Support Network to them, and (when time permits) taking their name and phone number or e-mail so that there can be follow-up later on are just a few suggestions that Dainty mentioned could make a huge difference in the bystander experience.

“Life after cardiac arrest for survivors, family members and bystanders involves coping with a new reality and the potential impact of such a traumatic event,” said Dainty. “By bringing awareness to what is now the “6th link” in the Cardiac Arrest Chain of Survival—Support & Recovery—we can to bring more resources to understanding how these lived experiences can inform the development and testing of support structures to ensure the best possible quality of life for survivors and an empowering experience that encourages bystanders to continue stepping up.”

SURVIVOR STORY: KELLY SAWYER

An 'overwhelming feeling of gratitude' coupled with a mission to help others

By Hilary Gates, MAEd, NRP

When Emergency Physician Kelly Sawyer chose a fellowship in Emergency Cardiac Care (ECC) and Resuscitation, she couldn't have predicted that she would be a patient on the receiving end of the very specialty she was studying.

It was near the end of her 2-year fellowship when she parked in the garage at Virginia Commonwealth University (VCU) to head to a meeting with two giants of resuscitation science, her colleagues, Michael Kurz, MD and Joseph Ornato, MD. They were set to discuss some conference abstracts around therapeutic hypothermia for sudden cardiac arrest (SCA) patients, but Sawyer wouldn't make the meeting.

On her way into the building, she became acutely dyspneic and light-headed and collapsed, the result of a pulmonary embolism. Nurses nearby came quickly to Sawyer's side. They determined EMS was needed since the ED was not nearby, and they identified her by her badge since she was barely conscious.

Medics from the Richmond Ambulance Authority (RAA) arrived to transport her to the ED. Sawyer remembers little from the incident, just that she kept instructing them to "call Michael."

Kurz indeed was in the VCU ED for Sawyer as her heart rate dropped and she lost a palpable pulse. The ED team restored her circulation with CPR and pressors, but she needed urgent surgery to remove the clot, as the clot was large and because the thrombolytics weren't going to act quickly enough. Sawyer was placed on cardiopulmonary bypass, therapeutic hypothermia, and surgeons opened her sternum to remove the clot.

Her total rehabilitation time was two weeks in the hospital, after which Sawyer returned home with her mom by her side.

"It was remarkable how quickly my body



After her cardiac arrest, Sawyer had healthcare workers, family and friends who could check in on her, and she says she benefitted from connections that most survivors probably don't have access to. (Photos: Kelly Sawyer)

I noticed how affected my family, colleagues and friends were by my sudden cardiac arrest.

—Kelly Sawyer

was deconditioned," Sawyer says. "I had such a hard time even getting out of bed, eating, much less doing cardiac rehab. I was only 30 years old!"

Sawyer had chosen VCU to study its highly regarded systems of care that surround SCA patients. She considered VCU pioneers, leaders in the field of resuscitation. But she didn't know that their systems approach was still rare in other hospitals. So her mission became to bring those systems of care to other institutions.

After she recovered from her own SCA,

Sawyer worked for five years on similar ECC systems in a Detroit hospital, and then moved to the Department of Emergency Medicine at the University of Pittsburgh. Sawyer's SCA work has led her again, ironic for a second time, to be the first author and co-chair of the AHA's writing group alongside Kurz on the Scientific Statement for Survivorship after Cardiac Arrest. The Statement emphasizes the need for attention to rehabilitation and recovery after SCA; it is also the impetus for the addition of the sixth link to the Chain of Survival in the latest

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update of Oct. 2020. Sawyer uses her own experiences to inform this guidance.

"I noticed how affected my family, colleagues and friends were by my SCA," she says. "I wasn't really awake, but later, when I wanted to fill in the gaps of my memory, I relied on them to help me and was acutely aware how traumatic these memories were for them. All of this has really changed my perspective on how to treat SCA patients and their caregivers."

Sawyer can also use yet another perspective in her quest to improve care for SCA survivors and their families. At the age of 18, she was diagnosed with Hodgkin's Lymphoma. The successful treatments and her experience with the disease led her to medical school, thinking she could improve the overall holistic care for cancer patients.

"Now in a different specialty, I'm also drawing from my years-long experience with cancer to inform the care surround an SCA survivor. I feel that care for SCA patients lacks some of the collaborative advocacy that oncology seems to have figured out," Sawyer says.

She also recognizes that while the AHA's new guidelines are a major step forward, the harder work revolves around implementation, education, awareness and resources. Hospital size matters, and Sawyer says many centers may lack the resources for a team approach to survivorship.

"We need a discharge plan with a checklist to help minimize the gaps for patients within the months after leaving the hospital. The physical domain is fairly well-captured, but we need to do better with psychological challenges and risks: anxiety, depression, caregiver stress, language issues, being able to organize tasks, and the 'why me?' question," Sawyer says.

After her own arrest, Sawyer had healthcare workers, family and friends who could check in on her, and she says she benefitted from connections that most survivors probably don't have access to. She met the RAA EMS providers and many of the team members who took care of her at VCU.

Sawyer decided to commission a wooden bench for the parking garage ramp where she collapsed, because she never wants another person to not be able to sit down if they're not feeling well.

"I have an overwhelming feeling of gratitude and connection to those who took care of me, many whom were my clinical partners before I was their patient," Sawyer says. "I hope my story is helpful to people, but the bottom line is that we need to pay more attention to survivorship."



"I hope my story is helpful to people, but we need to pay more attention to survivorship," says Sawyer.



Sawyer commissioned a wooden bench for the parking garage ramp where she collapsed.

SURVIVOR STORY: RICK CHAP

A long recovery journey brings lessons for health providers and community support systems

By Hilary Gates, MAEd, NRP

For Rick and Jennifer Chap, all five of the AHA's Chain of Survival links came together to lead to Rick's positive outcome. From Jennifer's early initiation of the emergency response system, to performing bystander CPR with help from the 9-1-1 call-taker, all the way through to therapeutic hypothermia and post-cardiac arrest care at the hospital, Rick made a full recovery from sudden cardiac arrest (SCA).

So in October 2020, when the AHA announced in their guidelines update the addition of a sixth link to this chain, it only seemed appropriate that Jennifer and Rick had already done their own research on this topic of survivorship. As a rescuer and a survivor, respectively, Jennifer and Rick have lived for the past eight years focusing on not only their own physical, cognitive and psychosocial needs, but also on other SCA survivors in their close community.

It was 2012 when Rick suffered an SCA. They were starting another day of working from home. Their cat, Buddy, was near Jennifer in her office, and Buddy began meowing loudly, as if he sensed something was wrong. Indeed, Rick had collapsed in the kitchen. Jennifer dialed 9-1-1, and with the help of the call-taker, performed CPR on her husband until Orlando Fire Department's EMS providers arrived. Rick spent a total of 11 days in the hospital.

In the years since, Rick and Jennifer have felt obligated to re-focus their marketing company's efforts on increasing the public's awareness and knowledge of SCA and the importance of these links in the chain of survival.

But these post-cardiac arrest years have not been easy for Rick as a survivor, nor for Jennifer as a rescuer. These struggles were not only in its immediate aftermath. Jennifer describes the recovery time as simply: "long," as the brain and body need so much time to heal.

Rick says, "We both think about it every day."

In the months following his discharge, Rick wanted more information than he was getting from follow-up appointments with cardiology and numerous rehab sessions. He says that medical providers were not in the frame of mind to help his emotional survival, instead focusing on the physiology of the post-arrest care.

"I was left to my own devices, trying to make sense of what happened to me," Rick says. He says he was aching for other stories, and he turned to social media to ask others in the survivor community about his future. "How was I supposed to live now? I wanted to know how to approach the rest of my life. I mean, if I only have a week left, I'm going to party!"

Jennifer, by Rick's side during his recovery in the hospital, was updated frequently but also felt knowledge gaps about Rick's future. After she watched Rick experience ICU mania and suffer short-term memory loss, Jennifer wondered, "Will he always be this way?"



Rick's care team describes his recovery time as "long." Both the brain and body need time to heal. (Photos: Jennifer Chap)

"This was the most disturbing," Jennifer says. "Rick had few social filters, and he was acting differently than normal. He wanted to go home, but I was terrified. What if it happens again? How was I going to manage? I felt very alone."

Both Rick and Jennifer describe cardiac rehab as one of the most helpful parts of the recovery.

Jen considered the cardiac rehab setting a "safe place." She says she would have liked some kind of integration of her own care during Rick's rehab. Instead, she sought her own resources. Upon Rick's discharge, Jennifer went into full caregiver mode and became the support and communicator for the whole family—without realizing how traumatized she was.

"While I saw a social worker at the hospital, it became clear to me that there was no aftercare plan for the rescuer or caregiver," Jennifer says.

Rick also believes that the setting would be a good place for providers to focus on survivorship health. "Cardiac rehab and emotional and psychosocial support of the survivor should go hand in hand," Rick says. "When the survivor is released from the hospital, there should be a means of communication for monitoring progress. The medical staff could follow up with the family and address problems."

In the years since his arrest, Rick has experienced a range of emotions and some cognitive deficits that make some settings difficult, and many times, others don't understand.

"Even though survivors look fine on the outside, on the inside, we've endured damage," he says. "I have no broken bones or bandages, but I had a massive shut down of my entire bodily function."

In fact, when Jennifer and Rick began socializing with friends, Rick sometimes struggled to remember his friends when they approached him.

"It was really weird—a friend would come over to me and I wouldn't recognize him!" Rick says he was mortified by this. "My friends wanted me to be back to normal."

Despite these challenges, both Jennifer and Rick have taken it upon themselves to find ways to heal. They initiated meeting those involved in Rick's care: dispatchers, EMS, the fire department, hospital, ICU and rehab.

They have also sought out and found a supportive community in the Sudden Cardiac Arrest Foundation (SCAF) and in gathering and speaking at conferences like Citizen CPR, where they bond with other survivors and caregivers.

Jennifer and Rick also co-founded Buddy CPR, a foundation that advocates CPR/AED and SCA awareness. They are certified CPR instructors and sometimes teach alongside the Orlando Fire Department. For both of them, the opportunity to share their story with others has been incredibly therapeutic. They are also in awe of the generosity and compassion they see in EMS providers.

"We'll never be able to thank everyone enough," Rick says. "It was the system that was in place that saved me. So many times, it doesn't work out. We feel so honored to be associated with them."

"If anyone understands how long this recovery is, it's EMS," Jennifer says. "I want to help EMS now. On a cardiac arrest call, I want EMS to walk up to CPR in progress—every time."

Though survivors look fine on the outside, on the inside we've endured damage. I have no broken bones or bandages, but I had a massive shutdown of my bodily function.



Since his arrest, Rick has experienced a range of emotions and cognitive deficits that make some settings difficult.

SURVIVOR STORY: MAURICE TROSCLAIR

How he came to be known as 'Miracle Meaux'

By Hilary Gates, MAEd, NRP

I got shocked so many times, I had one foot on each side of life and death the whole time. That's a very complex scenario to process.



SCA survivor Maurice Trosclair doesn't mince words when he talks about surviving a sudden cardiac arrest.

"What happened to me that day could have gone so tragically wrong, but it went so miraculously right," he says. "You've got no other choice but to be grateful. But you're a different person."

In February 2017, Trosclair had just completed his typical lunch-time jog at work near New Orleans, when he suffered his SCA. In the building's elevator returning to the gym, he collapsed.

Three bystanders, two of whom happened to be nurses, activated the chain of survival, and following multiple defibrillations and CPR, Trosclair's heart began beating again. In the hospital, the cardiologists implanted a stent to open Trosclair's blocked artery, and he made a full recovery.

In the months following his arrest, Trosclair was dubbed "Miracle Meaux" and established a foundation called "Heartbeat NOLA" to teach bystander CPR and fund AED purchases. Trosclair also uses his visibility as a jazz trombonist to play gigs in and around New Orleans that raised money for the foundation.

When the AHA published its newest guidelines and added the sixth link for attention to survivorship, Trosclair was pleased to see this focus on people like him.

"More attention should be paid to the SCA survivor's release from the hospital: there should be a checklist, a list of what to expect, something structured to give the family," he says. "When my mom had a stroke recently, I saw firsthand as a caregiver what an effective discharge looks like. We have an opportunity to use a model like this for SCA survivors."

After being released from the hospital, Trosclair said he and his wife, Nancy, had to immerse themselves in the educational part of the recovery. Neither had any knowledge about the range of possible outcomes that come with surviving an SCA.

"They strapped an external defibrillator to me which could shock at any time, and said, 'see you in two months!'" Trosclair says he felt like his mind was scrambled, likening it to a computer rebooting. "We had so many questions that were unanswered, and we were left alone to make sense of what just happened. I wanted to know: what is my new normal? Will I be the same? How soon will I be fully recovered?"



Trosclair says the "greatest thing ever" was to reunite with his rescuers, who have even attended his gigs. (Photos: Maurice Trosclair).

He also worries about what Nancy is dealing with: "She had to become the principal caregiver of something she knew nothing about."

Going back to work was also a challenge. Working in a highly technical field processing seismic data meant that Trosclair had mastered complicated workflows, many which had become second nature. But when he returned to his office, he realized he had to revisit some work processes.

Ultimately, Trosclair's electrophysiology study deemed him not a candidate for an implantable defibrillator. So for him, the mystery of his SCA isn't totally solved. He still worries about his cognitive abilities and wishes that data on survivors was used to help inform others.

"Can't we come up with a spectrum of expectations for survivor outcomes?" Trosclair asks. "With all the data around survivors, where am I on the spectrum of 1-10? Am I a 5? A 7? I've met survivors who can no longer talk, and I've met others who can't shut up!"

With the COVID-19 pandemic affecting the career livelihoods of

both Trosclair and his wife, they recently made the decision to sell their house, buy a camper and hit the road with their two dogs. Now visiting the southeast portions of the U.S. with a camper named "NOLA," they teach CPR classes at campsites, prominently display their AED and try to increase awareness around SCA.

Trosclair says the "greatest thing ever" was to reunite with all of his rescuers who've even attended his gigs, who were astonished that the ashen grey Trosclair they last saw in cardiac arrest is now performing music on stage.

Trosclair has also found comfort with his fellow SCA survivors, meeting many at the ECCU Conference held in New Orleans in December 2017. He feels that they share a very similar and peculiar grief.

"What are we going through? We mourn our own deaths, actually. I got shocked so many times, I had one foot on each side of life and death the whole time," says Trosclair. "That's a very complex scenario to process."

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