

“The Feelings I Get Inside”

by Jon Caswell



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Bob Scott of Woonsocket, R.I. knows a lot about chronic heart failure, from the inside. In 1998 he was playing volleyball to lose weight when he started having chest pain. Like many 48-year-old men, he ignored it. Visiting his mother at the hospital later that day, he told his father, a bypass survivor, about the pain. He suggested Bob visit the emergency room right then, but Bob said he'd come back the next day if the pain didn't go away. “About midnight I awoke with really bad chest pain,” Bob remembered. “It felt like someone was hitting me with a sledge hammer.”

He woke his wife Carol to take him to the hospital. While she dressed, he showered and realized they needed to call 9-1-1. That was the right decision because he was having a massive heart attack. At the hospital, emergency personnel worked to stabilize him, but there was a bad reaction between the nitroglycerin and another medication, and his heart started beating very slowly and almost stopped. After his medication was adjusted, he was transported to another hospital and told he needed a stent. They also found he'd had a silent heart attack earlier that had caused muscle damage.

Two weeks after the stent had been inserted, Bob returned to work as a maintenance man for the Woonsocket Housing Authority. But a year later he had difficulty breathing while on the job. After another ambulance ride and another catheterization, he was told he would need a single bypass. His ejection fraction was 27 percent, and the doctor, the same one who'd done his father's operation, told him he had a one-in-four chance of surviving the operation. Bob decided to take those odds.

During the surgery, MHI volunteers stayed with wife Carol in the waiting room, but Bob didn't join that chapter, which was in Providence. Bob and Carol had plenty on their plates – two years before they had adopted three siblings ages 9, 10 and 11

who had special needs. Then in 2005 his local hospital, Landmark Woonsocket Medical Center, opened its own cardiac unit, and they contacted Bob, who had been volunteering at the hospital, about starting a MHI chapter there. At the first organizational meeting 11 people joined, enough to create a satellite. By the next meeting, Bob had recruited nine more, enough to charter Chapter 338. Bob was elected president.

The damage to Bob's heart resulted in chronic heart failure (CHF), which has prevented him from returning to work. But it has not kept him on the sidelines of life. "I am the type of person that when I commit to something, I go full steam ahead," said Bob. He and Carol attended the Scottsdale convention in 2006 (and every one since).

After that, vice president Raul Fernandes recruited him to be on the first national Advocacy Committee, chaired by Al Phillips at the time. "I said, 'What's an advocate?' And he said, 'Don't worry, you'll learn,'" recalled Bob. After Al had to step down because of illness, Bob became chairman. He was also appointed an ARD in the Northeast Region by RD Priscilla Soucy and replaced Raul on the Board of Directors for the New England affiliate of the AHA. So much for not working!

Although advocacy is fairly new to MHI, the organization has become very active. There are two representatives from each region. A sub-committee of seven reviews issues forwarded from MHI members or the AHA to evaluate whether they should be taken up by MHI. "If the committee agrees to support an issue, we pass it on to the regional reps, who pass it along through You're the Cure," said Bob. You're the Cure is an AHA program that facilitates grassroots advocacy at the federal, state and local levels. Bob has also attended two Lobby Day events in Washington, D.C., as well as the Patient Advocacy Leadership Summit in North Carolina, where he was one of four MHI representatives. "At that conference I got to see how other organizations do advocacy, and as a result I helped make a presentation on advocacy at the Hartford convention last summer."

This past September Bob testified at a Social Security Disability conference in Baltimore. "I made a PowerPoint presentation on what it's like living with CHF," said Bob. "I never thought I'd be representing other heart patients



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to make it easier for people with heart disease to get Social Security Disability Insurance."

Bob has the total support of Carol, who has worked for 38 years as a dietary clerk at the Landmark Woonsocket Medical Center. "Although she is only five feet tall, Carol is a very big person who puts herself last," Bob said. "She had a lot more than the kids to take care of when I came home from the hospital, and she did a wonderful job. We've been married 31 years, and I could not ask for a better mate."

Obviously MHI takes up a lot of Bob's time, but all the kids are grown now, and MHI is something he feels passionate about. "I have been given a second chance in life," Bob said. "Although my CHF slows me down, I don't sit around feeling sorry for myself. I live every day to the fullest, and I very much like helping others. They say everyone has a purpose in life, and MHI is mine. My only wish is that I had gotten involved sooner. The feelings I get inside when I visit a patient or speak with a caregiver, well, it's hard to explain, but it's why I stay so involved in MHI." ❤️



ABOVE: (l to r) Carol Scott, Bob Scott, Margaret Elbert, and Raul Fernandes at the Scottsdale Convention

LEFT: Bob Scott and his wife Carol Scott at the San Antonio Convention

BELOW: Bob Scott (l) and members of the Rhode Island AHA advocacy team present a Grassroots Legislator award to Representative Patrick Kennedy

