



## Chari's Story

*Special thanks to Chari Frederick for sitting down with Megan Schroder of the Consumer Health Coalition to share her story. Her story exemplifies the need for a health care system that is patient-centered, patient-driven, and that makes the patient the "North Star" in their recovery.*

Until 4 years ago, Chari was a healthy and active 67 year-old who was passionate about advocacy and her community. Chari describes her experience in the health care system as a four-year journey that started with a fall at the grocery store and ended in a nightmare she is still struggling to accept today. "I was at the store," Chari said, "when I started to feel dizzy and fell. They took me to the hospital, where I went into emergency surgery to repair a hole in my heart." Chari described a quick recovery, saying she was back to her busy schedule in just a few weeks, though she noticed feeling unusually tired and worn out. "My recovery never really progressed past that point," Chari said, "and I started to worry that something else was going on." A primary care physician (PCP) diagnosed Chari with Type II Diabetes, and told her the condition could be monitored to control the dizziness and fatigue. With her health continuing to deteriorate, Chari sought a second opinion and said she could not believe it when she finally found a medical professional who would take her concerns seriously. Nearly two years had passed between the initial fall at the grocery store and the diagnosis Chari received with the new PCP: Hypertrophic Cardiomyopathy. "My heart was severely enlarged," Chari said, "and was not able to adequately pump blood, which caused the dizziness and weakness." With medication and a new PCP to monitor the condition, Chari scheduled an appointment with a cardiologist and slowed down the pace of her daily schedule while she waited. "I was scared and I was exhausted," she said. "One day, I was at the store and I had to sit down in the middle of the aisle. I was so tired, and I just could not get back up."

On Mother's Day, Chari attended a football game with her 10 year-old grandson. He scored a touchdown to win the game, and Chari jumped up to cheer and run down the field, not knowing how that day would end up changing her life. Halfway down the field, Chari started to feel dizzy and weak, then experienced a heart attack that caused her to fall, breaking her leg in several places as she hit the field. On the way to the hospital, Chari experienced an additional period of cardiac arrest, and upon arrival, taken into emergency surgery to install a pacemaker. "Most of the details are still hazy," she said, "but later I was able to read through my medical report to find out exactly what happened: I had been in recovery only a short time before I started to code, at which point they started a second emergency surgery to put in the defibrillator. I went into a coma, and woke up nearly one week later to my daughter's voice telling me to open my eyes. I could not talk, and had no idea what had happened. My leg was in a cast, and I was told that they had also found renal failure and damage to my liver and lungs."



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# News You Can Use

→ This link provides information on teaching literacy strategies for pharmacists! Thanks to our community partner, Joyce, for sharing this link!

<http://www.ahra.gov/pharmhealthlit/index.html#pharmlitqi>

→ How do we really know what a quality hospital looks like without the data to back it up? Check out this great article.

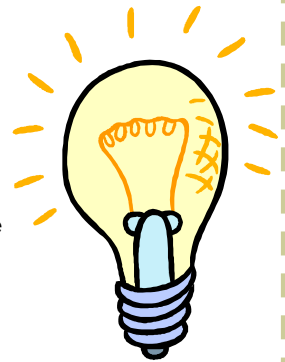
<http://www.post-gazette.com/pg/12001/1200345-432-0.stm>

→ Want to learn how to create an effective video to share your story? Check out this manual from the North Carolina Justice Center.

<http://www.ncjustice.org/sites/default/files/HAC%20-%20Video%20training%20manual.pdf>

→ The National Committee for Quality Assurance is finding that health care quality is on the rise! Check out their 2011 report!

<http://www.ncqa.org/LinkClick.aspx?fileticket=FpMqapADPo8%3d&tabid=836>



## Advocacy Toolbox - The Coleman Model

The Coleman Model was created by Dr. Eric Coleman, MD, MPH, of Colorado. Dr. Coleman found that a patient's condition and care needs change throughout the progression of their illness. In order to avoid costly readmissions and to create an environment that ensures that the needs of a patient are met between their transition from a hospital to home, he developed the Coleman Model. The model is based on four concepts which he has referred to as Pillars. These include:

1. Medication self-management
2. Use of a personal health record
3. Timely follow-up care
4. Knowledge of red flags indicating that your condition has worsened

Being your own self advocate, becoming engaged in your healthcare, and effectively communicating with your care team will not only lower your health care costs, but you will also allow you to be more likely to achieve your healthcare goals. To learn more about the Coleman Model please visit [www.caretransitions.org](http://www.caretransitions.org)



Care Transitions Intervention®

Attribution to Eric A. Coleman, MD, MPH

**Chari's story continued from page 1** One moment, Chari was delighted and celebrating with her grandson, and the next she was in the hospital with a week of blank time. "I was so worried about the mud on the field," Chari said, "that was what I kept thinking while in my hospital bed: that I had just been hoping not to fall in the mud while jumping and running down the field." The next couple of days, Chari said she was scared to move or breathe with the scar on her chest a constant reminder of how fragile her heart had become. "I can still feel the outline of the box and the wires," she said, "and even today I still get scared and panic when I think about what happened." At that point, Chari had spent a week in recovery and started to make progress. She was told an additional surgery was needed to fix the break in her leg, and with a steel plate and twelve screws in place, Chari got ready to leave the hospital and start rehabilitation.

With a detailed discharge plan and specific instructions about medication and physical therapy, Chari was told to expect four to six weeks at the post-hospital center. Chari was excited to heal and get back to her life, but it would be September, nearly four months later, when she would be healthy and stable enough to leave. "The experience caused a scar," Chari said, "not just physical, but on my heart, and on my mind." While at the post-hospital center, Chari developed a constant pain in her back and was also concerned about an ache in her leg, but was told she was fine and had nothing to worry about. Nearly one week later, staff continued to ignore the pain, and Chari called 911 on her cell phone. At the hospital, Chari was told she was severely dehydrated and her kidneys had started to shut down. She spent several days in the hospital with IV fluid and antibiotics, at which time her orthopedic doctor also stopped by to check on the progress of her leg: "I instantly knew something was wrong because of his face," Chari said. "He told me that the sutures had been scheduled to come out nearly two weeks ago, but were still in my leg. Not only that, but I had developed a staph infection."

"I knew I was not receiving the care I needed, but I had nowhere else to go," Chari said. "So I went back to the post-hospital center, again with a detailed and specific discharge plan. I hoped the quality of my care would improve because of the incident with the hospital, but it did not. I went eleven days without a bath, was not taken to the bathroom when I asked, and started to notice that my leg wound was being ignored." One day, Chari insisted that her leg needed to be properly bandaged and cleaned. The night nurse took off the bandages and looked down; with a shocked expression, she told Chari she could see the hardware in her leg and a hole in the ankle: "I started to panic, and asked to go back to the hospital. They told me it was not necessary, but I demanded it." While at the hospital, Chari had a total of four surgeries to fix the damage to her leg. Because the staph infection had progressed, Chari was told she could potentially lose her leg. Luckily, she said, they were able to save the leg and also completed a surgery to fix the hole in her ankle. While Chari had initially expected only four to six weeks in the post-hospital center, she now faced an additional ten weeks of antibiotics, rehabilitation, and physical therapy.

Today, despite the fact that Chari still faces struggles with her recovery, she continues to be a strong advocate and active in her community. In the midst of everything she experienced at the post-hospital center, Chari was able to recognize how quality and patient-centered care at her primary care physician's office and at the hospital helped support her recovery. Not only were medical staff available, at every step they told her what would happen and why; the discharge plan was comprehensive and clearly communicated; and the care was truly focused on Chari and her needs. The quality of care Chari received with her PCP and at the hospital was a stark contrast to the horrors endured at the post-hospital center, and it is that experience that Chari holds onto today. Chari's story highlights the need for persons to not only have a comprehensive hospital discharge plan, yet, also to make certain the plan is understood and coordinated with all parties involved in the transition of care.

## PA Campaign for Better Care

We all deserve comprehensive, coordinated health care. We get it. There is a better way!

The PA Campaign for Better Care (PA CBC) is a statewide campaign to secure quality, coordinated, and patient-centered care in PA. CHC is the driving force behind the Campaign here in PA, which was selected as one of six state-based campaigns along with Maine, Massachusetts, North Carolina, New Jersey, and Ohio. A partnership with Community Catalyst, a national healthcare advocacy organization, provides valuable oversight and guidance.

**Special thanks to the Program for Healthcare to Underserved Populations and the United Way of Beaver County for signing on to the Campaign.**





## CONSUMER HEALTH COALITION

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Consumer Health Coalition was founded in 1996. We are a non-profit health care advocacy organization with a mission to “inspire a consumer movement to advance health and enhance access to quality, affordable health care.”

We believe that access to quality, affordable health care, and ultimately good health and wellness, are critical to a person's ability to reach his or her potential. We also know that people experience disparate “starting points” or access to resources that are unfortunately correlated with socioeconomic status, racial or ethnic background, and disability status. CHC is dedicated to the eradication of disparities in health access and outcomes, and will continue pushing until every person has the health coverage and care they need.

## Mark your calendar for these important dates!

February 2012

### Monday, February 6, 2012

Healthy Hospitals Workgroup  
4:00 pm to 6:00 pm  
Location:  
CHC  
415 E Ohio St Suite 300  
Pittsburgh, PA 15212

### Thursday, February 9, 2012

PA CBC Conference Call  
The Coleman Model: A Hospital  
Discharge Plan  
10:00 am to 11:00 am  
Call-in: (712) 432-1630  
Access code: 411307#

### Tuesday, February 28, 2012

Lift Up Your Voice Training  
1 pm - 6 pm  
Bistro-To-Go—Northside  
Registration Closed for this event

March 2012

### Monday, March 5, 2012

Healthy Hospitals Workgroup  
6:00 pm to 7:30 pm  
Location:  
CHC  
415 E Ohio St Suite 300  
Pittsburgh, PA 15212

### Wednesday, March 7, 2012

Lift Up Your Voice Training  
10 am - 3 pm  
United Way of Beaver County  
Contact Leslie to register at  
412-456-1877 x200

### Thursday, March 8, 2012

PA CBC Conference Call  
The Affordable Care Act: Anniversary Update  
10:00 am to 11:00 am  
Call-in: (712) 432-1630  
Access code: 411307#

### Friday, March 23, 2012

Two Year Anniversary of the ACA!  
*Oral arguments before the Supreme Court begin on March 26 through March 28.*

### Wednesday, March 28, 2012

Advocacy Workshop  
2 pm - 4 pm  
Location - TBD