

# Cleveland Clinic Miller Family Heart & Vascular Institute

## Resources for Patients

### Patient Story: Battling Hypertrophic Cardiomyopathy

#### A Second – and First – Chance at Life

By all outward appearances, Tonya Wesley was a healthy 26-year-old when she went to the late show at a local movie theater 11 years ago.

But upon leaving the theater, she fainted and fell face forward, suffering a gash on her chin. At the hospital, the ER doctor noticed that she had a loud heart murmur. He referred her to a cardiologist, who diagnosed her with hypertrophic cardiomyopathy, or HCM.

HCM is a complex type of heart disease associated with a thickening of the heart muscle, most commonly at the septum — the muscular wall that separates the left and right side of the heart — just below the aortic valve. The passageway to the aorta can become too narrow and lead to infection, irregular heart rhythm, chest pain or angina, heart attack, stroke or death.

But for the next decade, Ms. Wesley lived with the condition, despite suffering from chest pains, shortness of breath and fatigue. It affected every aspect of her life, from working as a server to simply walking around the mall. She always attributed her physical difficulties to being out of shape, though she worked out relentlessly. “I wouldn’t admit that my heart condition was a problem,” she says.

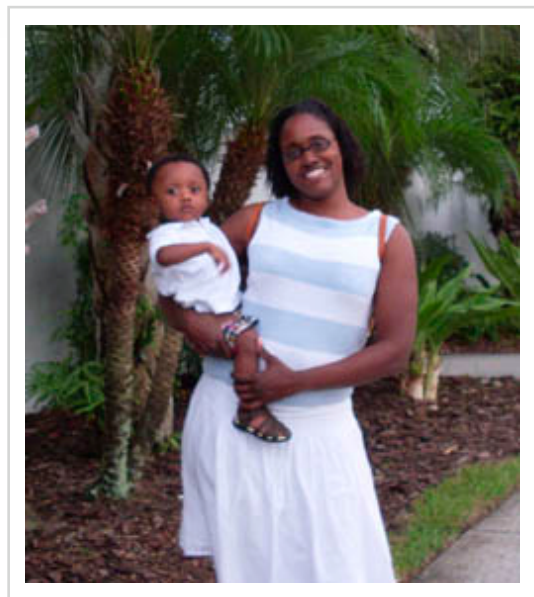
But she could ignore it no longer when, while 12 weeks pregnant, she had an episode in which her heart began to race, accompanied by chest pains and shortness of breath. “I thought I was having a heart attack and was going to die,” she recalls.

Once at the hospital, tests revealed that it wasn’t a heart attack, but, because of the HCM and her history of tachycardia, she was advised to have a defibrillator implanted. But the problem with implanting the defibrillator was the use of radiation, which is considered harmful to fetuses — especially during early development. The electrophysiologist thought it best to try to get her to Cleveland Clinic, where the procedure is performed with ultrasound and a minimal amount of radiation.

So she made the trip from her home in Charleston, W.Va., to Cleveland, where she learned that not only was the defibrillator a must, but the condition of her heart was not conducive to surviving a pregnancy. Prior to having a defibrillator implanted, she was recommended for a septal myectomy, a surgical procedure performed to reduce the muscle thickening in the heart. But it, too, was considered a threat to the baby.

Fortunately, Cleveland Clinic has one of the largest surgical practices for treating HCM. Its surgeons have been performing the septal myectomy procedure since 1967 and have done more than 1,600 myectomies to date.

Ms. Wesley placed her life — and her pregnancy — in the hands of Nicholas G. Smedira, MD, surgical director of the



Kaufman Center for Heart Failure, Cardiac Transplantation and Mechanical Circulatory Support. He also is director of quality for The Heart and Vascular Institute, Department of Thoracic and Cardiovascular Surgery.

The main risk was keeping a constant flow of oxygen to the uterus. Miscarriage also was a big concern. "My thought was I would rather lose the baby trying (surgery) than to abort it," she says.

She underwent the procedure in January 2008 and, not only was the surgery a success, but also her pregnancy. A healthy baby boy was born five months later, and Ms. Wesley says she is a new woman.

"I can walk stairs and exercise without feeling like there is an elephant standing on my chest. I can walk briskly without feeling lightheaded and can even incorporate a little jogging when I walk," she says, noting how important an activity it is now that her 14-month-old is walking.

And she can't say enough about her surgeon. "Dr. Smedira is an angel sent to me from God, and I truly believe that," she says. "If he hadn't the courage and the skill to do what he did while I was pregnant, my beautiful miracle of a son would not exist. Not only that, I felt as though he cared. I wasn't just another surgery he had to do."

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### Aorta Repair Patient Story

#### Going the Distance

With perhaps just two months to live, Emma Neubauer finds the courage to take a chance

#### **Emma Neubauer nearly skipped having life-saving surgery.**

The 88-year-old New Britain, Conn., resident was discouraged by the advice she got last fall at a hospital near her home about repairing her thoracic aneurysm.

"The doctor said it would be a very hard operation for me — very hard on me because of my age — so I backed out," Mrs. Neubauer recalls.

Fortunately, her med-student granddaughter had other ideas. Monica Jacobus, who started her residency in general surgery in Chicago this month, and her father went online in search of doctors who do endovascular repair. An alternative to open surgical repair, endovascular surgery involves making incisions into the groin area and threading stent-grafts up through the arteries to the diseased portion of the aorta.

#### **Their search led them to cardiac surgeon Eric Roselli, MD, at Cleveland Clinic.**

After evaluating Mrs. Neubauer, Dr. Roselli decided against going the endovascular route.

"He thought open surgery would do a better job for her," Ms. Jacobus said. "His skill and confidence really allowed her to understand that this was a good idea for her and she would have a lot more years of a healthy, happy life if she was willing to go through with it."

Without the surgery, Dr. Roselli estimates she had only two months to live.

So Mrs. Neubauer underwent the aortic repair at Cleveland Clinic on Dec. 18, 2008, spending the holidays in the hospital and her birthday in rehab. But she couldn't be happier with her ultimate decision.

"Last week, I was there for a checkup and Dr. Roselli was very pleased with the outcome, and he would like to see me in a year from now," she says.

"He's a wonderful doctor. He saved my life. I gave him big hug. If it wasn't for him, I wouldn't be here today."

#### **Of course, she also credits her caring family.**

"I was ready to give up on life itself, but my granddaughter would not hear of it," she says.

Ms. Jacobus insists that she didn't want to push her grandmother to do one thing or another, only to get her enough information to make an informed judgment. She also wanted to get a second opinion, from someone who would see beyond her grandmother's age.

"She's 88. I think a lot of people would have made a decision just looking at that number and say she's not a surgical candidate," Ms. Jacobus says. "But Dr. Roselli was actually willing to look at her. For an 88-year-old, she's really healthy."

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### Robotically Assisted Mitral Valve Surgery Patient Story

#### **Mommy feels great! One woman's triumph over mitral valve prolapse**

Her sister died suddenly at age 42 (married with three children). Her brother died at 37 (married with three children). So Connie Karcher, “*was a bundled mess of nerves*” when she was expecting her first child. She went to her doctor for a complete cardiac workup, and found the family pattern was continuing: she had mitral valve prolapse.

Although the leakage was mild at the time of her diagnosis, it got worse by the year. By the time her son was seven, her cardiologist told her, “*You need surgery. You need to have it now.*” Connie said: “*Stop right there. I've already decided upon the Cleveland Clinic.*”



The 45-year-old Perrysburg, Ohio resident had been researching valve replacement and repair on the Internet. Online, she discovered that Cleveland Clinic Miller Family Heart & Vascular Institute did more surgery for mitral valve prolapse than anyplace in the world. More importantly, for her, the Miller Family Heart & Vascular Institute offered robotically assisted mitral valve surgery.

“*I didn't want to join the zipper club,*” she recalls. “*Plus, I could reassure my family that I was having my surgery at the world-renowned Cleveland Clinic, with the outstanding surgeon Dr. Tomislav Mihaljevic.*”

In Cleveland, she and her husband met with Dr. Mihaljevic, who explained the procedure in detail. “*With robotic surgery,*” Connie says, “*recovery is a matter of weeks, rather than months. There are no blood transfusions involved. Just three tiny incisions. Less chance of infection.*”

Connie had her surgery on a Monday. “*I was in the ICU, brushing my teeth and combing my hair, same day.*” By Tuesday, she was out of the ICU. By Friday, she was out of the hospital.

When she first arrived home, her children ran to her. But they were wary of hugging. They were worried that hugging her might hurt her. “*But I told them,*” Connie says, “*The surgery was a success. Mommy feels great!*”

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### Patient Story: Heart Surgery Patient

#### Patient Story: Ken Dockery



On a clear day in June, Ken Dockery parked his bicycle at the front entrance of Cleveland Clinic. Inside, he rode the elevator to the 10th floor of the Miller Family Heart & Vascular Institute. The doors slid open, and he stepped out, back into the unit where he'd spent six days recovering from open heart surgery two and a half years before. He stood in the hallway, silent, reflective.

Quiet sobs drew his attention. Nearby, a woman sat alone, head bowed. She moved to let Mr. Dockery sit beside her. "My husband is a heart patient here," she explained. "He's stopped taking phone calls from family and friends; he doesn't want to live."

Mr. Dockery locked his eyes on hers and began his story — how he'd been diagnosed with a heart disorder at 34; how he'd begged the doctors to delay surgery so he could spend Christmas with his family; how he started biking every day during rehab to regain his strength. Finally, he shared the reason he was there that day. He was in the middle of a 500-mile bike ride, beginning at his home in Pennsylvania and ending at his parents' home in Detroit, to raise money for Cleveland Clinic's heart program.

The woman stood up. "Will you talk to my husband?" she asked. Mr. Dockery entered the man's room and shared his story. "Before I left," Mr. Dockery recalls, "he asked me to move his telephone down to his bed so he could take calls. His wife wept." Inspiring hope — this is Ken Dockery's mission.

"I spent six days on the 10th floor really evaluating my life," he says. "America is so focused on getting the promotion, getting to retirement.... I couldn't look that far ahead. I started thinking, 'What am I going to give back?'" So far, Mr. Dockery has finished two bike rides, which he calls the "Inspire Hope" tours. In all, he's raised \$5,000 for Cleveland Clinic's new Heart and Vascular Institute, scheduled for completion in the fall of 2008.

While delivering the second donation, Mr. Dockery learned of Cleveland Clinic's advertising campaign, Letters to Tomorrow. The letters, which focus what patients look forward to doing after surgery, inspired him to write one of his own. Here is an excerpt: "Don't get used to having me around because I do not intend on staying long," he wrote, remembering how he felt as he went into surgery. He continued: "...Hello again Room 100-23. I just had to stop by for a visit. I know that it has been 17 months since I was here, but I just had to stop and say, 'I told you so.'" This summer, Mr. Dockery is planning a third bike ride, the "Inspire Hope: Coast to Coast" tour, which will begin in Oregon and end in New Hampshire — more than 3,600 miles. "We're all here for one reason," he says.

"We're here for hope. That's what this place was to me."